

**National Disability Insurance Scheme**

**Consultation paper: Access and Eligibility Policy with Independent Assessments**

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**Response by**

**Motor Neurone Disease NSW Special Interest Group**

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## **PART A**

The following submission has been prepared by and on behalf of the Motor Neurone Disease (MND) NSW Special Interest Group (SIG), representing over 1000 allied health professionals from around Australia. The MND NSW SIG are a committed, multidisciplinary team of health professionals with extensive experience in assessing and supporting people living with MND within the framework of the NDIS.

### **Preamble**

MND NSW is a small not for profit organisation working to support nearly 600 people living with MND and their families each year across NSW, ACT and NT. The organisation has over 40 years' experience in working with people with MND as well as in understanding this disease, its progression and the approaches that ensure best outcomes. MND NSW were part of the pilot of the NDIS in the Hunter region and have continued to work with participants within the scheme, both assisting them to secure access and also in coordinating and operationalising approved plan supports.

The MND NSW SIG network is an important partner in ensuring appropriate and timely support is provided to people living with MND. The group is an essential part of educating the entire MND community about MND, its progression and importantly, how to achieve a good and inclusive life, irrespective of functional impacts.

It is our opinion that people with MND should be exempted from being included in an Independent Assessor (IA) pathway to acceptance to the National Disability Insurance Scheme (NDIS). As this submission will outline, IAs have the potential to significantly disadvantage people living with MND, cause greater emotional distress, and represent an untenable time burden for receiving funding and support under the scheme.

### **What is Motor Neurone Disease (MND)?**

MND is a rapidly progressive neurological disease for which there is currently no known cure or treatment. Each person diagnosed with MND will experience onset, progression, and duration differently, with few markers, particularly early in disease progression, as to how and at what rate individual disease will progress. For this reason, people living with MND will be connected, in the early stages, to a range of health professionals with expertise in MND, and who will remain with them, in the majority of cases, until their death. Where possible, continued support is also provided by specialist MND multi-disciplinary clinics.

MND is an umbrella term encompassing a range of motor impairments caused by the death of motor neurones. MND does not directly impact sensory or autonomic pathways. It may, however, include cognitive losses, and in some cases the dementia MND overlap presents as a co-morbidity. In the early stages, loss may be localised but over time, functional deficit will increase, often with irregular patterning, and respiratory compromise as the muscles that support breathing are impacted. Importantly, people with MND can and do live valued and engaged lives with the right supports, including assistive technologies and a multi-disciplinary approach, irrespective of disease stage or progression.

### **MND and Individual Assessments**

Given the rapid change in functional ability experienced by people living with Motor Neuron Disease, tools that have been tested in this population and/or have the ability to predict future functioning, should be considered. Reviewing previous function, as per the IA framework for participants with Motor Neuron Disease, will likely mean key information related to the rapid progress and functional changes that will occur with MND, will be missed. The suitability of an adaptive behavioural assessment for people with MND should ultimately be reconsidered.

While the WHO Disability Assessment Schedule (WHODAS) includes a participation domain, the focus is on community and social engagement. Whereas, participation assessments should be extended to consider meaningful engagement and choice across all activities. The WHODAS assessment misses key information connected to engagement in activities, as well as, instrumental activities of daily living, that is valued by the person and no longer able to carry out.

Environmental assessment, as described in the IA framework, is based on self-report by the individual and their support team and therefore, reflects recent experiences only. The assessments in the IA framework do not allow for consideration of future functioning which is especially important for a progressive neurological condition, such as MND. The quality of information in self-report assessments are reliant on the capacity and/or willingness of the responder to provide responses that are reflective of their function.

Additionally, specialised assessment of the environment should be undertaken by an expert health professional in collaboration with an individual with MND, e.g., an occupational therapist in terms of physical environment and suitability with everyday activities, and speech therapist in terms of communication. People who are newly diagnosed with MND are unlikely to have the knowledge of the disease to understand how their functional decline can be affected by the environment. Given the rapid progress of MND, appropriate environmental reviews should be included, as part of the NDIS package, and not be built from the results of IA alone.

## **PART B**

### **Discussion Questions**

***1. What will people who apply for the NDIS need to know about the independent assessments process? How this information is best provided?***

For people, particularly when newly diagnosed with MND, the language of disability is particularly foreign. This language barrier causes significant issues for people living with MND. Therefore, there needs to be a robust approach to ensuring future participants have a good understanding of, not only the mechanics of applying for funding through the NDIS,

but also of the concepts and assessments that underly and inform successful acceptance to the scheme.

For this reason, we believe that future participants will need:

- Information about Independent Assessments in terms of
  - What it is?
  - How it works?
  - What information needs to be provided and why?
  - The scope of information that needs to be provided, such as how they are on their best and worst days, as well as the current gaps in their support, any informal supports that can be regularly relied upon, and other environmental contextual information.
- To be able to articulate how the support they require may change over the life of a potential NDIS Plan. This is something that is vitally important for people with MND, and others with rapidly changing conditions.
- Information and support to understand the language of the NDIS and disability sector. To appropriately differentiate between formal and informal supports in their conversations with Assessors, as well as to minimise misunderstanding or confusion of what they are asking for or needing.
- Support to clearly outline their vision of what they want their life to look like, assistance in identifying what they need to support their goals, and to be enabled to live a life as well as possible, as expected by a person without a disability. This will allow the person with MND to discuss in a meaningful way, how they want to participate in their day-to-day life. This information is not captured in the IA framework as participation focuses only on community and social activities.
- An understanding of their own disability and insight into its functional impacts now and into the future.
- Prior knowledge of the types and scope of the assessments they will be asked to undertake. We particularly note that people with MND fatigue easily and may also experience emotional distress when responding to questions and discussing their disability, over an extended period of time. Fatigue is a real issue that will need to be considered in the roll out of IA for most people with disability.

- Understanding from Assessors that people with MND are usually applying for NDIS funding, very soon after diagnosis. Many will be overwhelmed and dealing with the grief and loss associated with diagnosis. Information regarding IA, and the significance of these assessments may need to be provided several times, and at several stages throughout the application process, to ensure that the participant has time to process and understand what they have been told.
- To understand how the IA process affects them in accessing the support and services they need now, and in the months and years following.

## **2. *What should we consider in removing the access lists?***

We recommend that consideration be given to not removing immediate access for diseases such as MND, for which there is no question of lifelong impact, and that they continue to be provided with automatic acceptance to the NDIS.

This position draws from the following:

- MND is progressive and debilitating disease with no cure nor accepted treatment.
- People with MND can present very differently from one another, particularly in the early part of their disease progression.
- Everyone with MND will experience functional decline but the rate varies with each individual. Assessment, therefore, is required more frequently to identify support and services, according to their specific need.
- If function, at time of access request, is the only marker for inclusion in the Scheme, then this provides an additional layer of burden for people living with MND. People living with MND potentially will need to revisit the access process several times before acceptance, causing not only additional distress, but importantly delays to the receipt of appropriate supports.
- We already experience significant delays in accessing supports under the current arrangements for new Scheme participants. Given the nature of MND, there is concern that an IA, who will be unknown to the person (information sharing requires trust), will mean further delays to receipt of supports, particularly if they have to source additional information.

- It is inevitable that Assessors will require information from known health care professionals involved with the person living with MND. Given, that this is already occurring and working well for people with MND, layering yet another assessment would seem to be a redundant duplication of resources. Additionally, this opens the potential for a duplication of administration processes, which may lead to delays and additional costs to both the NDIS, and potential participant. In relation to people living with MND, this administration process may potentially need to be repeated more frequently, leading to a fragmented and uncoordinated (not seamless) assessment process.

**3. *How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is, or is likely to be, permanent and life long?***

A person living with MND will often have been involved with many health professionals over an extended period of time, before they receive their final diagnosis. Confirmation of diagnosis is made by a specialist neurologist with experience in MND.

We would note:

- Once a diagnosis of MND is made there is no question about lifelong functional impact.
- Diagnosis from treating health professional, such as a neurologist, with an accompanying supporting letter will provide adequate evidence of diagnosis and lifelong impact.
- It is imperative to have a functional report from a comprehensive multidisciplinary team (MDT) clearly outlining what the person living with MND can and can't do in everyday life, and with reference to their preferences for meaningful engagement. This report should be built on a comprehensive assessment that allows the MDT team to share their expert knowledge. All MND participants cannot be boxed into one type or stream of funding.

#### **4. How should we make the distinction between disability and chronic, acute, or palliative health conditions clearer?**

MND is a disability that is progressive and requires supportive care interventions delivered from a palliative perspective. This should be integrated into the care planning early after diagnosis to achieve the best participant outcomes. Irrespective of disease progression, the focus remains that disability, health and care should align to maximise functional ability and emotional wellbeing, whilst simultaneously managing disease progression. We note that this supports the tenets of palliative care as prescribed by the World Health Organisation (2008) which includes in its definition of palliative care:

- Supports to help individuals live as actively as possible until death.
- Uses a team approach to address needs.
- Enhances quality of life and positively influences disease progression.
- Is applicable early in disease course in conjunction with other therapies.

We know that palliative care interventions are often being implemented too late and it's important that palliative care be considered more positively in improving an individual's capacity to manage MND progression, as well as supporting the role of disability and healthcare services. We need to change perceptions of palliative care from being only about end-of-life care, to reframe its place in disability to be about quality-of-life care, to enable someone to live as well as possible with their disability. It is vital that IAs understand the importance of adopting this approach to ensure assessment and funding reflects this.

#### **5. What are the skills and traits you want in an assessor?**

Most people with a disability are exposed to a range of health professionals, support workers and government officials over their lifetime. Almost universally, people living with MND, find this incredibly distressing, particularly as many of these people will only be a part of their lives for a short timeframe. Therefore, the ability to build a trustful relationship with the person being assessed will take considerable skill and must also appreciate that those being assessed will not, in all instances, engage fully with the process.

In the case of MND, participants have heightened concerns that the people involved in the assessment process have the necessary knowledge and understanding on the overall management of MND. They want to be reassured of the competency of people involved in decision making, through the allocation of funding that accurately reflects need. Independent Assessors also need to be cognisant of the challenges faced by people recently diagnosed with MND, particularly when having to relay the details of their diagnosis, dwindling abilities, and the palliative nature of the disease. It is not uncommon for current NDIS Planners, to ask how long a participant will live for, and to make determinations on support based on their own subjective views of how long a participant will most likely use a support. The reality is that some people with MND will live more than 5 years and others 10, and no one is in a position of surety to identify who these people will be on an individual level. Therefore, an assessor, needs the skills and experience to set aside preconceived ideas of longevity and make assessments based on what the person needs now and in the immediate future.

Additionally, it is vital that an Independent Assessor be:

- Experienced with the condition of the person they are assessing and its lifelong impacts.
- A person who is well trained in all aspects of assessing a person's function considering biomechanical, sensory, cognitive, psychosocial etc. aspects of the condition. Including an understanding of the need to source the most suitable environment and means for the assessment to take place. They should also be sensitive to managing fatigue during the process, and be prepared and able to, reduce assessment to smaller segments.
- Skilled in undertaking assessments with people who have a communication impairment, and who may rely on assistive technologies.
- A professional who is empathic, responsive and who considers the impacts of MND on both the person and their families, including younger carers. As well as be someone who considers family dynamics and recognises the limitations for informal supports to be involved with or deliver complex care.
- An effective communicator who is able to facilitate a shared decision-making process.

- Comfortable with the different types of emotions associated with living with a disability and palliative illness. Have the ability to reframe questions that may be sensitive or inappropriate for a person with MND and be confident in navigating this.
- Prepared and carefully consider the invasive and distressing effects of constant re-telling of a person's condition, illness, or disability.
- A suitably qualified professional holding appropriate qualifications together with relevant experience in an allied health field.
- Experienced in working with individuals with complex and unpredictable disabilities and have a familiarity with their subsequent needs.
- Current in their knowledge of a diverse range of available assistive technology options for mobility, transfer, activities of everyday living, positioning, pressure care, and alternative and augmentative communication.
- Approachable, empathic, and able to engender trust very quickly.

**6. *What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?***

It is well understood that people with disability find unfamiliar settings such as offices and assessment centres incredibly confronting. Many are so overwhelmed that they are either unable to express their needs or present as they would in their ordinary day-to-day lives. This means that actual need may be understated. Understating need could potentially be exacerbated when they have no prior relationship with the person assessing, and therefore do not feel comfortable in discussing their situation in depth.

Most importantly, it is vital that people living with MND are assessed in their home environments, so that a wholistic view can be formed about their ability to maintain independence within the full range of their day-to-day activities. These activities could include continuing to be able to be actively involved in the care, schooling, and social activities of dependent children.

We note:

- People with MND and other disabilities find it hard to access locations for assessment and prefer their own homes or another safe, accessible, and familiar environment.
- Trust is a significant issue and having someone who is known to the person being assessed is important to the accuracy of information obtained in the assessment.
- Often people feel quite vulnerable and overwhelmed with the process of assessment, fearing they may fail in some way, therefore having a good, trusting relationship with the person undertaking the assessment is important. Additionally, it is equally important that during the assessment the person is supported by someone known to them who can act as an advocate, when necessary.
- Assessors must be confident, capable, and respectful in undertaking assessments in a variety of settings, including a person's home.
- In some cases, the opportunity for video conferencing may be preferred, particularly within the context of the current pandemic and with regard to the respiratory vulnerabilities of people living with MND.
- Fatigue can, as mentioned elsewhere in this submission, greatly impact the person's ability to manage the assessment process, irrespective of the location. We therefore strongly recommend that assessment/s be completed in manageable '*chunks*'.
- Many people living with MND use Augmentative and Alternative Communication (AAC) devices and should be given the opportunity to participate in any assessment utilising these devices.
- We strongly recommend that the assessor be appointed from within the persons current allied health team who is a trusted key worker, and could work more effectively to complete assessments within the new assessment framework.

***7. How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?***

MND does not discriminate. People from indigenous communities, culturally diverse and non-English speaking backgrounds, and those from socially disadvantaged backgrounds, are equally affected by this disease. They are however, more often unable to access appropriate

support in a timely way. We are also aware that standardised assessments for these cohorts are often ineffective if unable to be implemented with cultural adjustments.

In addition, we recommend:

- Formal registered interpreter services are utilised during assessments, and that people living with MND /carers/families have sufficient time to build trust in the assessor and assessment process.
- Ensure that the full battery of assessments are culturally sensitive and framed.
- That printed and audio-visual resources in relation to independent assessment are available in a variety of languages and formats.
- Assessors undertake cultural awareness training provided by a suitable organisation external to the NDIA, and are cognisant of a future participant's cultural beliefs, prior to assessment, to ensure cultural sensitivity is maintained throughout the process.
- Questions regarding cultural practices, beliefs, rituals are embedded as part of any assessment.
- Have available assessors who are able to communicate within the language of the future participant.

***8. What are the limited circumstances which may lead to a person not needing to complete an independent assessment?***

It is our strongest recommendation that people with MND and other rapidly progressive neurological disorders are exempted from the independent assessment process. Complex conditions such as MND, which have varied and rapidly changing functional deficits, do not lend themselves to a standardised intake process, and require additional sensitivities in their management. It may also be true that such future participants may be medically unwell, and/ or processing complex grief and shock, at the time of a potential assessment.

Understandably the early stages of diagnosis are the most challenging for individuals and their families, and therefore to overlay additional complex assessments, represent an unfair and disproportionate burden to this cohort.

Burden and disadvantage may also stem from the assessment batteries used by an independent assessment, which are focused on current function. However, with an illness such as MND, we know that a person's function can change dramatically over a few days. For this population, consideration for predictive planning to avoid multiple and burdensome reviews is necessary.

Particularly within the palliative aspects of care for people living with MND, many of the questions asked in assessments would be difficult to answer, and not appropriate. For example, questions in the WHODAS, such as 'in the past 30 days how much difficulty have you had in learning a new task or how much difficulty have you had in analysing and finding solutions to problems in day-to-day life?'. Neither of these questions have meaning or relevance for a person living with MND.

Most importantly, MND is an absolute diagnosis from which there is no reprieve.

***9. How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?***

Participants will expect all assessments to be provided by assessors who apply, interpret, and deliver nationally consistent outcomes. This will require continual scrutiny of Independent Assessors adherence to approved process, as well as audit of reporting against anticipated outcomes for particular disabilities.

This further requires that:

- There is a mandated minimum standard for all assessors, and that appointed independent assessment organisations are prohibited from engaging inexperienced allied health professionals/assessors and must employ a key assessor to provide supervision.
- All appeal processes need to be sensitive to the time needs of people with MND, and an escalation pathway clearly identified and committed to, by the NDIA.
- There is a clearly articulated pathway for participants and /or family members, allied health care professionals and any coordinator of supports , involved with the participants, to provide specific feedback about the independent assessment

experience and if needed, to be able to provide contra evidence or opinion about the functional needs of the person being assessed.

- There be authentic consumer engagement in the design, approach, ongoing development and monitoring of the independent assessment pathway and individuals delivering this service, on behalf of the NDIA.
- Disability disease-specific organisations, health professional groups etc., also be involved in monitoring the effectiveness and implementation of independent assessment, as advocates for the participants.
- Comprehensive data collection and monitoring to provide regular open reporting on the need for early plan review following an independent assessment, to determine if the process is adequately provisioning for participants actual needs.

#### ***10. How should we provide the assessment results to the person applying for the NDIS?***

There is a current gap in the ways in which NDIA Participant Plans are provided to participants. It becomes the responsibility of an appointed Coordinator of Support to retrospectively explain plan meeting outcomes, or in their absence, the Local Area Coordinator who may also lack the practical experience of the persons disability or disease, to provide appropriate interpretation of funding outcomes. We also note that the Coordinator of Support will be appointed after the plan has been received by the participant, which leaves a time gap between plan generation and the participants full understanding of what has been approved.

For this reason, many people with an NDIS plan do not understand what has been provided, how funds may be allocated and what redress they have if funding does not meet their specific needs. It becomes critical therefore to:

- Have the independent assessor and plan approver set aside appropriate time with the participant to explain the outcome and funding impact of their assessment.
- Encourage other family members or advocates to be present when plans and funding are explained to participants, as this can be an overwhelming process, requiring additional support.

- Provide comprehensive feedback both verbally and in writing. Participants report that they find the current format of a written letter, and possible quick phone call or email about next steps, confusing and time delaying.
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