NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

Consultation paper: Access and Eligibility Policy with independent assessments

Submitted by:

MND Australia

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Background

MND Australia, its research arm, MND Research Australia, and members, the State MND Associations, form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND) and advancing research to end MND. For 40 years this national network has helped increase understanding of the disease and advocated for improvements in its treatment and care to ensure people living with MND have the best quality-of-life possible. The six state MND Associations provide direct support and services to people living with MND in all states and territories. Together this network represents people living with MND, their carers, family and friends and the health, disability and aged care service providers involved in their care across Australia.

ABOUT MND

MND is the name given to a group of neurological diseases in which motor neurons, the nerve cells that control the movement of voluntary muscles, progressively weaken and die. With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues. MND affects each person differently with respect to initial symptoms, rate and pattern of progression, and survival time. **The median survival is 2 to 5 years, although approximately 20% 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 older[3]. There is no known cause for MND (except in a very small number 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 preventing and/or delaying 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% 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.

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[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

MND AND INDEPENDENT ASSESSESSMENT

It is crucial to recognise that 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. Expert assessment and planning is therefore vital due to complex and progressive decline in functional abilities. It is essential that assessment and planning are undertaken by people who have in depth understanding of the person and the disease.

MND Australia, in partnership with our members, has engaged proactively and successfully with the NDIA since the introduction of the NDIS to support an effective planning process for people living with MND and their planners. This led to the development of the first disability/disease specific MND practice guide for planners and an understanding that it was not appropriate for local area coordinators (LAC's) to undertake planning for people 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. At the local level MND Associations have provided training, information and support to planners involved in working with people living with MND thereby assisting the process and helping planners to understand the complex and individual nature of MND. 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 progressing conditions.

People with a disability that is complex and has potential to progress rapidly should be exempt from undertaking an independent assessment in order to access the NDIS.

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 will be missed.

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 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 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 their environment.

Plans need to be developed that take rapid progression into account without the need for an independent assessment each time there is functional change. Without this flexibility the NDIA will be wasting 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 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.

To date skilled planners have been integral to successful plan development and implementation for people living with MND. The MND Associations have worked closely with the NDIA in developing guidelines, relationships and communication pathways to ensure people with MND receive timely and relevant plans and support (see recent case study). The introduction of independent assessments appears to separate and minimise the role of planners. It is difficult to understand how plan development under this new framework will support the person to receive the reasonable and necessary supports to meet their goals as per the original premise of the NDIS.

It is also unclear how section 25 of the Act, 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.

An example of vital early intervention is accessing Speech Pathology before loss of speech is experienced. 8 out of 10 people with MND will experience changes to, or loss of, speech. The impact of such a devastating symptom can be lessened through proactive and pre-emptive measures to identify assistive and alternative communication methods such as voice banking. This is an intensive process that is recommended to commence immediately after diagnosis before symptoms progress and reduce the likelihood of success. Being able to communicate wants and needs is essential for choice and control.

The introduction of independent assessments and the proposed planning policy will undo progress made for people living with 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 progressing conditions.

MND Australia recommends:

1. People living with progressive, degenerative neurological and/or neuromuscular conditions who have potential to progress rapidly (e.g. MND), based on the expert opinion of their specialist doctor, must be placed on the list of exemptions to negate the need for an assessment every time a person experiences functional decline and to support early intervention.

2. The Independent Assessment Framework be amended to ensure that people living with progressive, degenerative neurological 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 Independent 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 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. 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.

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.

Feedback on the consultation questions:

Our national MND network strongly believes that 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.

Answers to the guiding questions have been provided below, however these answers have been provided reluctantly and only because the content of the guiding questions indicate that the NDIA is committed to the implementation of IA’s. From the questions posed it is clear that the NDIA is simply seeking guidance on aspects of implementation and impact rather than engaging with the community to understand the implications of these major changes. We wish to make it clear at the outset that, in regard to people with MND and other progressive neurological conditions, IA’s will be an unmitigated disaster. Our intention in answering the questions is to attempt to mitigate some of this risk. These answers should in no way, be seen as an endorsement of the reforms. In attempting to provide answers and workable solutions, it has further highlighted the potential for dire consequences of the proposed changes for people with MND and other progressive neurological conditions.

Learning about the NDIS

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

Clear, concise and accessible information is vital for people applying to access the NDIS. Information and support must be provided to help them understand the language of the NDIS and the disability sector. The meaning of terms used such as formal and informal supports and what can and cannot be funded through the NDIS needs to be clearly explained to assist them to prepare for an independent assessment. Information should be provided in a format specified by the person applying to take into account their communication and accessibility needs.

Support organisations such as an MND Association can assist and support people recently diagnosed, many of whom will be overwhelmed and dealing with the grief and loss associated with this devastating diagnosis. They can assist the person to prepare for an independent assessment and come to terms with the fact that their condition will progress and their function decline. We have long campaigned for the role of support organisations in supporting people to prepare for planning meetings and assessments to be recognised by the NDIA as a vital service that should be appropriately funded by the government.

As highlighted in the recent case example people living with MND may progress rapidly following diagnosis and fatigue may impact profoundly. People will therefore need to know what is involved, how long the process will take and how long they will need to wait until supports can be accessed.

There must be understanding from Assessors that people with MND are usually applying for the NDIS very soon after diagnosis and are still coming to terms with its future impacts on them and their family.

People who apply for the NDIS will also need to know:

- About their condition and how it might impact them in the future.
- What the NDIS is and how it works
- What supporting information will be needed and reviewed i.e. a doctor's letter outlining their condition and likely progression
- Who will be able to support them through the assessment process and be with them at the meeting
- How the assessors are delegated and their understanding and experience of the person's disease or disability type
- How they will be informed regarding the date/time of the assessment
- The time frames for completion of assessments
- Where assessments will take place and how long they will take
- What assessments will be undertaken and what support and information is available to help the person prepare for them
- What will happen as their disability progresses or changes
- How IA are in keeping with the stated object of participants having choice and control
- When they can expect to get a copy of their IA
- How they can appeal against a decision as a result of the report from the IA
- How the IA process affects them in accessing what they need now, and in the weeks, months and years following.

Accessing the NDIS

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

The significant risk that this will create to the physical and psychological wellbeing of people with MND.

Consideration must be given to the impact of removing the access list for people with conditions that are always lifelong, progressively debilitating and have no effective treatments like MND.

Consideration must be given to exempt those with complex and rapidly progressing conditions from the independent assessment process.

Each person diagnosed with MND will present differently. As illustrated in the case study example (Appendix 1) if access to the scheme is based on function at time of the independent assessment it is likely that people living with MND will need to undertake repeated independent assessments before being accepted into the scheme. This will cause much distress, delays to receipt of appropriate supports and limit the opportunity to live a meaningful life in the time left to them. Everyone with MND will experience functional decline, but the rate and pattern will vary and be difficult to predict in the early stages. Assessment is therefore required more frequently to identify support and services to address specific needs.

In addition consider:

- How the needs of clients with condition such as MND will be addressed adequately by this assessment process
- How resources developed for planners to date including the internal MND Practice Guide will be utilised under the proposed new model
- How assessors will be educated on the needs of people with complex and progressing conditions
- How quickly people with living with progressive, degenerative neurological and/or neuromuscular conditions will get their access request actioned
- How to manage the assessment process for people with progressive, degenerative neurological and/or neuromuscular conditions
- The impact of avoidable hospital admissions that may occur as a result of delays in access.

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 with MND accessing the NDIS will have already been through a long diagnostic process, in some cases 12 to 18 months, involving myriad health professionals. A diagnosis of MND it is always permanent and lifelong and a letter from the diagnosing or treating neurologist will be adequate evidence of diagnosis and lifelong impact.

In addition:

- Understand that certain conditions are complex and are always permanent and lifelong like MND.

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

MND is life limiting and a palliative approach is therefore required from diagnosis onwards to support the person to achieve the best outcomes and to live as well as possible, with the best possible quality of life until end of life. There must be an understanding that for people with a diagnosis of MND and other degenerative neurological or neuromuscular diseases a coordinated multi and inter-disciplinary approach involving disability, health and palliative care services is required. A team based approach to care, with the NDIS funding and addressing needs that are related to a person's disability, is crucial in maintaining independence and quality of life. It is vital that Independent Assessors understand this palliative approach to care and the availability, or lack of availability, of other mainstream services in a person's local community in order to ensure that an appropriate plan and budget are developed.

Undertaking an independent assessment

5. What are the traits and skills that you most want in an assessor?

We strongly recommend that people living with progressive, degenerative neurological and/or neuromuscular conditions are assessed by specialists with knowledge and experience of working with people living with these conditions using appropriate assessment tools.

As already outlined a person diagnosed with MND will require care and support from a range of health professionals and disability service providers from diagnosis through to end of life. This can be extremely distressing as many of these people will only be a part of their lives for a short time and have little knowledge of MND. Having to constantly relay the details of their diagnosis, progressive loss of function and ability, as well as the palliative nature of the disease is stressful and distressing.

MND Associations have reported many instances of current NDIS Planners asking participants how long they are expected to live, which is a question that is impossible for them to know the answer to. They then develop plans that will fund supports based on their own view of how long the participant will most likely live. The reality is that some people with MND will live for 5 to 10 years[4,5] and no one is in a position to identify who these people will be at a planning meeting or through an independent assessment. An assessor therefore needs the skills, experience and understanding of the person's condition to assess them based on what they need now and in the coming months.

In addition assessors will need:

- To have background knowledge, qualifications and understanding of the diagnosis/disability
- To be active listeners when it comes to the person's needs and how the disability impacts on their day to day life
- Have experience of, or be trained in, undertaking assessments with people who use assistive technology to communicate
- To understand that people with disability are often reluctant to report decline in function or think about future loss of function and ability
- Knowledge of, and be up to date on, the types of assistive technology that can be used to support people to mobilise, transfer, undertake their usual activities of daily living, position themselves and maintain comfort and communication
- To be 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?

People living with MND should be assessed at home unless the person specifies they do not want this. A face to face home assessment will ensure that a holistic view can be formed about their functional ability, independence and informal supports in their usual environment. This also provides the opportunity to assess how the person can be supported to maintain their role in the family such as continuing to work and be actively involved in the care, schooling, and social activities of dependent children.

As our recent case study illustrates the impact of fatigue needs to be taken into account. We recommend that the Independent 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 wherever possible. It should be noted, however, that in some states or regions an applicant will not have access to a local allied health care team further highlighting the need for specialist assessors.

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

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

We also support the recommendation from the MND NSW Special Interest Group that the assessor be appointed from within the person's current allied health team who is a trusted by the participant and could work more effectively to complete assessments within the new assessment framework. Again this would only apply if the person has access to such a team.

In addition:

- Find out prior to holding the assessment about the person's condition and how they are able to communicate as they may need a longer appointment if they are having trouble with their speech or suffering from fatigue
- Become familiar with the type of communication device they use before the meeting
- Allow others including family members, MND Association Advisor and health professionals such as a member of their allied health care team or Support Coordinator to be a part of the assessment process
- Offer appointments by telehealth or allow family members to join the meeting virtually
- Offer appointments in the evenings and at weekends.

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

MND affects people from all cultures, nationalities and backgrounds.

Independent assessments therefore need to:

- Ensure that interpreter services are available if and when appropriate
- Ensure that people have sufficient time to build trust in the assessor and assessment process
- Inform the person that other members of their family, community or support team are able to attend the independent assessment – in person or virtually
- Be delivered in a way that takes account of the person's environmental situation and needs (housing, accessibility, supports, family network, access to the community, equipment, and communication)
- Provide culturally suitable resources ahead of the meeting and find out if anything should be taken into consideration from a cultural perspective before the appointment
- Have information on independent assessments in a variety of languages and formats available on the NDIS website.

Exemptions

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

As previously stated we strongly recommend that people with MND and other rapidly progressive neurological conditions are exempted from the independent assessment process. Being forced to undertake an assessment in order to enter the scheme shortly following diagnosis whilst still processing complex grief and shock will be distressing and challenging.

In addition, as the recent case study highlights, the person may be fatigued and struggling to adjust to rapidly progressing functional decline. It is highly likely that the person and their family will have little insight into the impact of progression on their lives and the interventions they will need to support them at this stage. It is evident that the assessment tools will not be sensitive to the needs of people with complex conditions like MND nor able to assess future functional decline and needs.

The current model whereby the planner understands the need for a timely response and is guided by the MND Practice Guide in developing a plan is working well and should be continued through an independent assessment exemption for this cohort.

Most importantly this diagnosis is always progressive, lifelong and fatal. Forcing people to spend precious time undertaking repeated assessments when the current planning process, in most cases, is working well for people with MND is burdensome, unnecessary and does not support the principle NDIS tenets of choice and control.

Quality assurance

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

Quality independent assessments for people living with MND will depend upon ensuring that their assessors have appropriate allied health qualifications and understand MND and its impacts.

This further requires that:

- There are minimum standards and accreditation in place for all assessors and that the independent assessment organisations are funded to appoint only experienced allied health professionals to undertake all assessments
- That independent assessment organisations are funded to undertake disease and disability specific training
- There is a process in place to gather direct feedback from the participant themselves and a robust complaints and review process
- Feedback from the providers is supported and encouraged
- There is an NDIS feedback email for participants and providers regarding independent assessments
- There is a direct NDIS contact person with a full name, email address, phone number for the participant and support coordinator to be able to contact. Rather than the 1800 number
- Have KPI’s around how assessors’ performance is measured.

Communications and accessibility of information

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

The person applying for the NDIS should be informed as soon as possible about the outcomes of the IA phone or email and a face to face meeting organised irrespective of whether the person is deemed eligible or not. They should also be provided with a copy of the assessment results rather than just a summary as proposed.

The results of the assessment will determine whether a person is eligible to access the scheme based on whether they have reduced functional capacity to undertake any of the six activity domains in the NDIS Act. As already stated, under the proposed independent assessment process, using the assessment tools proposed, it is likely that some people recently diagnosed with MND, having a 'typical day' when assessed, will be deemed ineligible. They should, therefore, be provided with the results at a face to face meeting and be provided with information about what to do and how to access the scheme as their function declines. If they are expected to wait a minimum of 3 months before they can be assessed again then comprehensive feedback both verbally and in writing will be imperative and once again highlights the inadequacies of this process for people with MND.

If a person is deemed eligible then an NDIS delegate will consider a budget based on the assessment and identify any additional supports required. It is proposed that the participant will then receive a draft plan and a draft plan budget and a planning conversation will take place. It is imperative that the planner and assessor meet with the participant, and any other family members or support people, to discuss how the assessment results have informed the development of the draft plan and budget. This process will need to be clearly explained verbally and in writing with clear information regarding time frames and next steps.

MND Australia thanks the National Disability Insurance Agency for the opportunity to respond to this consultation paper on independent assessments. We would be pleased to provide further information if required.

Carol Birks,
CEO, MND Australia

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 works with MND Victoria and his treating health professionals to submit 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 he has been functioning around the house and does not ask about how fast his condition is progressing or about how MND might impact his future needs. She 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.