MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Joint Standing Committee on the NDIS inquiry into independent assessments under the NDIS

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Introduction

MS Australia is pleased to provide a submission to the Joint Standing Committee on the NDIS inquiry into independent assessments under the NDIS.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS) and other neurological conditions for which our state organisations provide services and support. The comments have been provided by representatives of our state organisations who assist people to navigate the NDIS and in some instances, directly from people living with MS. MS Australia's role is to work on behalf of all of our state and territory-based member organisations to provide a voice for people living with MS across the country.

MSA's member organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MSL (Multiple Sclerosis Limited providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services to people living with multiple sclerosis regardless of age, and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

Introduction of mandatory assessments

On 7 September 2020, the NDIA released a new NDIS Functional Capacity Assessment Framework with the stated aim to provide "the evidence base and principles to inform the introduction of best practice Independent Assessments".

As part of the implementation of this new Framework, in mid-2021 independent assessments will be required as part of the NDIS access process, and, from the end of 2021 independent assessments will be required as part of the plan review process.

The implementation of this new Framework is of great concern to the MS community. Of particular concern is the negative impact the Framework will have on NDIS participants and prospective participants living with MS.

These concerns are perpetuated by media reports about people that have already experienced independent assessments describing the process as "de-humanising" and using a "tick box" system.

Summary of recommendations

This submission makes the following recommendations:

Recommendation 1:
MS Australia recommends that the Framework be amended to ensure that the provision of functional capacity assessments and additional supporting information from members of an applicant's or participant's health care team is provided for through the issuing of improved clarification and guidelines.

Recommendation 2:
MS Australia recommends that the NDIA postpone the implementation of independent assessments until the second pilot can be completed, outcomes determined, evaluated and corroborated with the first pilot report, and any revisions to the Framework considered in consultation with the disability community.

Recommendation 3:
MS Australia recommends that the Framework be amended to ensure that people living with progressive, degenerative neurological and/or neuromuscular conditions are assessed by assessors with specialist knowledge and experience of working with people living with MS.

Recommendation 4:
MS Australia recommends that the Framework ensure people with an NDIS plan who have been hospitalised and require an NDIS plan review, should have their assessment prioritised.

Terms of reference

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

The announcement of the introduction of Independent Assessments to the NDIS has caused a great deal of anxiety for the MS community who are NDIS participants and for those who we are assisting with NDIS applications. Applicants and participants need stability and security with their NDIS applications and plans, without the spectre of further assessments by assessors they do not know and that may not have a good understanding of their chronic condition. We also concerned that the proposed framework has been rushed, will be inefficient and has the potential to add considerable distress and trauma to the lives of people living with disability associated with their MS.

We believe that the new Framework is at odds with the recommendations of the Tune Review, specifically, paragraph 4.37 of the Report which states:
"4.37 Therefore, this review considers that, in at least the short term, the NDIA **should not** implement a closed or deliberatively limited panel of providers to undertake functional capacity assessments. Rather, engagement issues need to be monitored closely and the panel of approved providers should be dynamic and evolve to ensure the new approach does not drive disengagement. Where structural or localised engagement risks are identified, the NDIA should actively engage with participants and

the market to ensure the availability of appropriate providers of functional capacity assessments.” [1]

We have argued below that “appropriate providers” are those that have specialist expertise, including a thorough understanding of MS, the often invisible symptoms experienced, variability of presentation at diagnosis and functional impact.

Set out below are comments (not their real names) received via MS Australia’s social media channels from members of the MS community:

Sue: It’s typical of the government to roll out something with potential and when people make use of the scheme they take away the opportunities it was meant to give. The new system will make it even harder to get NDIS and some of us will lose it completely. Disability pensioners didn’t receive an increase during the pandemic. Our expenses increased too. We are becoming the ignored and forgotten once again.

Jane: IA will mean, as far as I understand it, people will assess me with no knowledge of my MS, imagine I'd have a good day- my funding will be gone, as they won't realise I might be immobile, non verbal and nearly blind the next day? I hope I'm wrong!

Sally: Not my choice. I’m not in control. IA goes against the foundation statements upon which the NDIS has been built.

Bob: I’m firmly against the proposed reforms- IAs, changes to what is reasonable & necessary, loss of appeal rights and the use of invalid tools such as the WHODAS which has been modified by the NDIS. Thus making the tool invalid & it’s assumptions

“Sympathy bias” unfounded

The reference in the Framework to the ‘sympathy bias’ of the participants’ allied health professionals (as a reason and justification for introducing “independent assessments”) undermines the professional ethics of the profession of which they are bound to by the Australian Health Practitioner Regulation Agency (AHPRA). The NDIA has mistaken ‘sympathy bias’ for in-depth and reflective clinical reasoning.

It is acknowledged that the NDIA has valid concerns regarding the current consistency and quality of functional capacity assessments. It has always been an area of frustration for allied health professionals working in the MS space, that the NDIS does not provide clear guidance and templates for functional capacity assessments. We would have preferred that, rather than introducing independent assessments, improved clarification and guidelines be provided to allied health professionals. This would enable participants to continue to utilise their familiar supports but improve the consistency of reports back to the NDIS and provide the accuracy that is likely to be absent from a report completed by an independent assessor within the specified timeframe.

A key element that is missing from the Framework is the lack of personalised knowledge that providers gain from working with clients that assists in providing them with

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[1] https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-insurance-scheme/review-of-the-ndis-act-report, paragraph 4.37

accurate funding. This knowledge, about matters such as the home environment, family support, and commitment to therapy are only gained over time and should be included in the assessment of required funds.

In the Framework (page 24) it is stated that, “there are some complex circumstances where supplementary information will be needed for an NDIS delegate to examine before a final decision can be reached. In these circumstances, the suite of assessments will form the solid foundations upon which the decision will be made, with supplementary details providing the scaffolding and reinforcement to shore up any gaps that may appear”. Also, on page 25 of the Framework it says, “NDIS decisions may need to take into account supplementary information for some participants/prospective participants”. MS Australia believes that consideration of this material is essential for the assessment of people living with MS.

Recommendation 1:
MS Australia recommends that the Framework be amended to ensure that the provision of functional capacity assessments and additional supporting information from members of an applicant’s or participant’s health care team is provided for through the issuing of improved clarification and guidelines.

Trialling independent assessments

In the development phase, the first pilot of 500 participants was limited to people with intellectual disability, psychosocial disability and autism.

We understand that this first pilot group did not include people with progressive, degenerative conditions such as MS that have personalised timeframes, that is, the disease journey for everyone with MS is different, everyone progresses at their own rate. This is an important factor to be considered when developing a standardised assessment process.

At this stage, the report of this initial pilot has yet to be released. The second pilot resumed at the end of October 2020 and expanded on the initial trial, though total numbers have not been confirmed, nor range of participants (including disability, state/territory, age or gender).

In the first pilot, only 28% (145) out of the 512 people involved in the pilot completed the NDIA feedback survey. Of those only 35 were NDIS participants, while the remining 110 responses received were from carers.[2] It is also worth noting that responses could be made at any time after the assessment; meaning a positive assessment result would more likely be reflected in a positive review of the process. MS Australia considers this level of testing to be inadequate given the results will inform policy that will affect more than 400,000 people across the nation.

Comments (not their real names) received via MS Australia’s social media channels from members of the MS community regarding the second pilot:

Vicki: I volunteered to take part in the NDIS National Disability Insurance Scheme

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[2] https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:%22committees/estimate/1bad3d3e-80f8-498e-a93b-585809f8dd26/0000%22

#independentassessment right up until I found out that a family member or a carer would be questioned about me, without me present.
My participation was then no longer required.
If that’s how it’s going to be, it is wrong and a dealbreaker.

Karen: Likewise. An absolute dealbreaker. I withdrew from the pilot at that point.

Early intervention

For people with progressive neurological conditions like MS, the Early Intervention (EI) pathway is an important access route for relevant and pivotal supports, particularly when a person is on the trajectory to – but does not yet meet – the “substantially reduced functional capacity” criteria. These are irremediable conditions, with fluctuating functional impacts, and certainly have a trajectory to meet the Scheme’s full access criteria within the lifetime of the participant. Therefore, it is critical that these conditions have a streamlined access pathway to the Scheme prior to the substantially reduced functional impact, of which Early Intervention is the most appropriate access point. Automation of this access decision will assist with the other caveats which underpin the intention of Early Intervention, that is, to mitigate or alleviate, prevent deterioration, or improve functional capacity.

Given the variability of presentation at diagnosis and functional impact (which can be minimal at that point) and also the instability of disease until 6-12 months post diagnosis, assessment of likely impact of functional capacity at diagnosis is often a challenge in clinical practice.

Any person with MS who has just been diagnosed, has never received funding for supports/services for their functional impairments, or has begun to have functional impacts (i.e. progression of MS), ***should meet EI criteria inherently.***

Automatic access to EI for these incurable conditions will assist with streamlining access decisions for people with MS, and potentially other similarly presenting incurable progressive neurological conditions, and thus reduce the need for alternative systems such as Independent Assessments to achieve the same result.

Recommendation 2:
MS Australia recommends that the NDIA postpone the implementation of independent assessments until the second pilot can be completed, outcomes determined, evaluated and corroborated with the first pilot report, and any revisions to the Framework considered in consultation with the disability community.

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

A possible comparison in another jurisdiction is the introduction of standardised testing within schools. Whilst there have been many arguments for and against this policy, one of the main arguments relevant to this submission, is that this form of testing in schools has been shown to be ineffective as it does not take into account the different learning patterns and styles of children. Similarly, regarding all people with MS as the same through the application of standardised assessment tools, negates consideration of the personalised nature of their condition.

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

MS Australia is concerned that the resources required to successfully implement independent assessments may not have been accurately captured by the NDIS.

The effective development and implementation of an NDIS plan, requires some level of knowledge about the participant and their life to build accurate goals. It is impossible to determine how someone's condition affects their goals without spending time visiting with and talking to the individual. This cannot be done via the timeframes anticipated in the Framework.

While it may seem to be more cost and time effective to outsource the role of assessments to independent entities, we remain concerned that the process of independent assessments will result in additional work requiring to be undertaken by allied health professionals, Support Co-ordinators, Local Area Co-ordinators and/or staff from advocacy agencies to address and overcome poorly informed or poorly constructed assessments of participants needs.

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

One of our main concerns with the introduction of the Framework is the ability of independent assessors to understand progressive, degenerative neurological conditions such as MS.

Without the appropriate training and extensive experience of working with people with MS, it is likely that the unique characteristics of the condition may be overlooked or understated as the assessor will not have any understanding of how the condition progresses or how symptoms impact upon functional ability.

We are also concerned about the accuracy of an assessment that is to be made following "a 20-minute (minimum) interaction or observation session" with the person before the assessor writes their report. The NDIA states on their webpage the assessment will take from the "1-4 hours" which is unlikely to produce an accurate report if the assessor has little or no knowledge and experience of MS. MS can affect all areas of a persons' function; it is not feasible to complete a thorough assessment, document and write a report on all domains of function in 1-4 hours.

In terms of the need for multiple sessions to assess people with complex needs, we acknowledge that page 25 of the Framework states that through the use of appropriate assessment tools, "these assessments also allow for functional capacity to be considered over a longer period and in a variety of settings, providing insight into the real world experiences of an individual in a time and cost effective way". It remains unclear how the need for multiple sessions is determined or how arrangements for these sessions will be made in practice.

How “independent” is independent?

As the assessors were hired through an NDIA tender process, the question remains, how independent are they really? This aspect of the Framework may result in the disengagement foreshadowed in the Tune Review Report and an overall lack of trust in the process.

Many people with a disability take years to develop a trusted network of supports surrounding them, and the introduction of independent assessors undermines the trust developed between a participant and their allied health professionals; discrediting the significant body of evidence to support the benefit of a therapeutic relationship. The introduction of an independent assessor is anticipated to cause a significant deal of stress to the participant and be detrimental to their wellbeing.

The Tune Review recommended (article 4.37) that where an independent provider is not available; non-NDIA approved providers may undertake the assessment. This should allow for specialised assessment, particularly for those not exactly covered by the NDIS disability nomination process.

Recommendation 3:
MS Australia recommends that the Framework be amended to ensure that people living with progressive, degenerative neurological and/or neuromuscular conditions are assessed by assessors with specialist knowledge and experience of working with people living with MS.

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

People with MS can often present with significant cognitive deficits including limited insight, which may lead to inaccurate reporting by the participant. The independent assessor will likely not have sufficient time to assess this in detail, nor have knowledge of the participant/applicant to know if this is present and if further assessment is required.

MS is often unpredictable and fluctuating, so, as outlined above, it is essential that the assessment of the individual is conducted over multiple sessions to gain an accurate understanding of the functional impacts for the individual. Assessing an individual’s capacity, as if it is a fixed, observable fact will not lead to accurate reporting or successful outcomes.

The Framework states that the approach to the independent assessment should be aligned to the International Classification of Functioning (ICF) framework. The ICF framework focuses on the ‘best’ a person can achieve at any given time. It is likely that an independent assessor using this framework to underpin their assessment will not allow for the fluctuation or disease progression experienced by a person living with MS, likely leading to a poor outcome for the participant and result in even more complaints and the need for plan reviews.

It is essential that the assessment tools used take into account the unpredictable and fluctuating conditions experienced by people with MS, that MS is well understood by the assessor and assessment tools applied using specialist knowledge and experience.

Informal feedback from Local Area Coordinators indicates that KPI's do exist to bring about plan value reduction so we are concerned that the accuracy of assessments may be comprised if the goal is to reduce the plan value from the outset.

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

The introduction of independent assessments is a concerning move away from the social model of disability to a medical model and significantly removes control from people with disability and their trusted supports, who are experts in their own support needs. The decision to introduce independent assessments and the proposed model highlights the need for the NDIA to work in partnership with people with disability to co-design reforms that adequately address needs, do not negatively impact participants nor undermine trust and confidence in the NDIS.

With the introduction of mandatory independent assessments we expect people with disability to face increased difficulty accessing the scheme and negative consequences due to inadequate provision of disability supports, leading to overall disengagement with the NDIS.

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

It is anticipated that the need for plan reviews and complaints will increase as the independent assessment will not be reflective of the participant's invisible symptoms and fluctuating functional capacity. Accordingly, this will result in increased costs to the NDIA and the participant as they need to seek additional reports from allied health professionals familiar with their disease journey.

In the case of rapidly deteriorating neurological conditions, the time spent on reviews due to inaccurate plans can result in missed opportunities for earlier, more effective support and thus an increased reliance on the hospital system and overall shorter life-expectancy.

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

These circumstances include where the assessor may be assessed as at risk in relation to their safety and where the consumer may be assessed at risk in relation to their safety including where the process of an in-depth assessment with an unknown person will cause harm or distress to the participant.

If a participant already has specialised allied health supports in place these providers should be able to provide functional capacity assessments to support access and planning, funded by the NDIS. The NDIS should provide a template and standardised assessments for existing providers to utilise, to provide the consistency and equity the NDIS is seeking. This will ensure best and accurate outcomes of the functional capacity assessment, as the assessment is based on a therapeutic relationship and specialised knowledge and experience.

9. Opportunities to review or challenge the outcomes of independent assessments

Advocates across the disability sector are extremely concerned by the inability to appeal an independent assessment, because it is considered independent of the NDIS, despite reports that appeals against NDIS decisions have increased by more than 700 per cent since 2016.

There is a significant lack of transparency in the decision-making process. It has not been made clear when or whether an individual will be provided the full results of their assessment, meaning that an individual may be unaware of the information being used in planning and deciding their funding. There is also little recourse for individuals who do not agree with an assessment, as the NDIA states that result will not be a “reviewable decision”.

10. 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

In addition to the comments above about our concerns regarding the appropriateness of independent assessments for peopling living with MS, we are concerned about the impact of these assessments on the diverse communities served by our MS organisations.

We understand that the Framework claims to be designed so as “to reduce the impact of any financial, social, cultural and functional barriers that may exist for an individual approaching the scheme at Access” (page 27). We are also aware that the Framework states (page 29), “It should also be noted that there are extenuating circumstances where there will be no option but to have an assessor who knows the person they are assessing, particularly in rural, remote and hard to reach populations. In these situations any risk of sympathy bias is outweighed by the need to complete the assessment process and to do so in a culturally-sensitive manner.”

Whilst these statements are made in the Framework, it remains unclear how the reduction in impact will be achieved or how the “extenuating circumstances” are defined.

This further reiterates the need for our recommendation that the Framework be amended to ensure that people living with complex conditions such as MS are assessed by assessors with specialist knowledge and experience of working with people living with MS.

11. The appropriateness of independent assessments for people with particular disability types, including psychosocial disability

In response to this term of reference we reiterate two points made previously.

Firstly, that without appropriate training and extensive experience of working with people with MS, it is likely that the unique characteristics of the condition may be overlooked or understated as the assessor will not have any understanding of how the condition progresses or how symptoms impact upon functional ability.

Secondly, that MS is often unpredictable and fluctuating, so, it is essential that any assessment of the individual is conducted over multiple sessions to gain an accurate understanding of the functional impacts for the individual. Assessing an individual's capacity, as if it is a fixed, observable fact will not lead to accurate reporting or successful outcomes.

12. Any other related matters

Change of circumstances

For people with an NDIS plan, who may have been hospitalised for say a fall or an MS relapse and needing their plan to be reviewed, we understand that information from the allied health team at the hospital, already linked in with the participant, will not be considered. For these people, they must wait until no longer hospitalized until they can be assessed by an Independent Assessor. Will NDIS prioritise these assessments to ensure people are not being kept in hospital due to delays in the process, or being discharged home without supports as the hospital cannot keep the person in while awaiting an NDIS assessor?

Recommendation 4:
MS Australia recommends that the Framework ensure people with an NDIS plan who have been hospitalised and require an NDIS plan review, should have their assessment prioritised.

KEY FACTS ABOUT MS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.