

A Report on the Impact of the Introduction of the Functional Capacity Assessment Framework on People Living with MS

Introduction

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, we understand that in early 2021 independent assessments will be required as part of the access process, and, from mid-2021 independent assessments will be required as part of the plan review process.

The implementation of this new Framework is of great concern to MS Australia’s state MS organisations, who provide support and deliver services to people living with MS and other neurological conditions in each state and territory. Of particular concern is the negative impact the Framework will have on participants and prospective participants.

These concerns and questions arising are set out below.

Inconsistency with Tune Review recommendations

The new Framework seems to be 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 deliberately 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

Trialing independent assessments

The first trial of 500 participants was limited to people with intellectual disability, psychosocial disability and Autism. We understand that the larger scale trial did not go ahead as planned this year, due to the impact of the COVID-19 pandemic. We further understand that the trial will be

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

recommencing in October 2020. Will this trial include people with MS and/or other neurological conditions?

We recommend that the NDIA postpone the implementation of independent assessments until the trial can be completed, outcomes determined and any revisions to the Framework considered.

Anxiety for NDIS participants

The announcement of the new Framework has caused a great deal of anxiety to scheme participants. Will they continue to receive the services they require if the NDIA implements this approach and discounts the information provided by therapists that have had long-term engagement and is considered by them to have better understanding of their requirements?

How “independent” is independent?

If the assessors are hired through an NDIA tender process, how independent will they really be? 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.

Lack of ability of assessors to understand a progressive, degenerative neurological condition like MS

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.

Without the appropriate training and experience of working with people with MS it is likely that the invisible symptoms of the disability may be overlooked or understated as the assessor will not have any understanding of how these symptoms impact upon functional ability.

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 client to know if this is present and if further assessment is required.

As MS can affect all areas of a persons’ function it is not feasible to complete a thorough assessment, documentation and report writing of all domains of function in 1-4 hours.

MS is an unpredictable and fluctuating condition, so 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 for people living with MS.

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

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 in condition usually experienced by a person with MS likely leading to a poor outcome for the participant.

Lack of understanding of MS by other areas within the NDIS (especially planners) and the high level of complaints from participants with MS and plan reviews, led to MS Australia producing a MS 'snapshot' document and video for use by NDIA staff, though there is little evidence that this resource is making any improvements to the interactions people with MS have with the NDIS. We are concerned that the introduction of independent assessments by assessors with little or no experience of MS will exacerbate this lack of understanding and result in even more complaints and plan reviews.

We recommend that the Framework be amended to ensure that people with MS are assessed by assessors with knowledge and experience of working with people living with MS.

"Sympathy bias" unfounded

The reference in the Framework to the 'sympathy bias' of the participants' allied health professionals 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. To date, it has always been an area of frustration for allied health professionals that the NDIS does not provide clear guidance and templates for functional capacity assessments. We would therefore advocate 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.

We recommend that the 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 through the issuing of improved clarification and guidelines.

Independent assessments in rural, regional and remote areas

People living in rural, regional and remote areas of Australia are currently already waiting months for services such as Occupational and Physiotherapy. The introduction of independent assessments will no doubt create longer delays for people living in these areas.

The independent assessment process

Concerns have been expressed to us about the degree to which an assessment relies on the knowledge and understanding of MS by the allied health assessors vs that provided by neurologists and MS specialised health professionals, given they are excluded from the process.

The process raises further questions:

- Is there going to be 'further supporting evidence' forms still allowed, or will the application be solely determined by the evidence of the independent assessment?
- How will people be able to challenge a rejection from the NDIS? Will they then be able to provide further supporting evidence from their own health professionals or be subjected to another independent assessment?
- Will NDIS applicants aged 64 be prioritised to get an independent assessment?
- When will the time of an application be determined? When the potential participant contacted the NDIS requesting access or the time the assessment is completed?

Access to information

When exactly will applicants and participants be able to access their own information from the independent assessments?

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, and instead the person will need to wait until being 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?

We recommend that the Framework ensure people with an NDIS plan who have been hospitalised and require an NDIS plan review, should have their assessment prioritised.

Release of Independent Assessment Toolkit

The NDIA has recently release the Independent Assessment Toolkit and we will assess its suitability for use in assessing people living with MS and other progressive, degenerative, neurological conditions.
