NEUROLOGICAL ALLIANCE AUSTRALIA

SUBMISSION

Joint Standing Committee on the National Disability Insurance Scheme inquiry into independent assessments under the NDIS.

31 March 2021

Executive Summary

The Neurological Alliance Australia (NAA) is a collective of national not-for-profit peak organisations representing nearly 1.3 million adults and children living with progressive neurological or neuro-muscular conditions in Australia.

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 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 members of the NAA. While this broad group represents conditions with various characteristics, trajectories, and life expectancy, all are degenerative and incurable. Of particular concern is the negative impact the Framework will have on NDIS participants and prospective participants.

These concerns shared by our communities 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:
We recommend 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 mandated through the issuing of improved clarification and guidelines.

Recommendation 2:

We recommend that the NDIA postpone the implementation of independent assessments until the second pilot can be completed, outcomes determined and corroborated with the first pilot report, and any revisions to the Framework considered.

Recommendation 3:
We recommend that the Framework be amended to require and 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 these conditions.

Recommendation 4:
The NAA strongly recommends that assessments are transparent, accountable and reviewable, allowing participants to appeal a decision or to provide further information as required to ensure their needs and goals are central to the application process.

Recommendation 5:
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.

Recommendation 6:
We recommend that the Framework include processes to meet the needs of people needing urgent adjustments to higher levels of care in response to crisis situations.

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 those in our communities 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. They also need the flexibility to manage their changing needs, without the spectre of further assessments by assessors who may not have a good enough understanding of their chronic condition.

We are 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 progressive disability associated with neurological conditions.

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 progressive, degenerative, neurological and/or neuromuscular conditions such as those represented by the members of the NAA.

"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 to which they are bound 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 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 without sufficient in-depth understanding of the complex and often poorly understood conditions our organisations represent, and within the specified timeframe.

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". The NAA believes that consideration of supplementary material is essential for the assessment of people living with progressive, degenerative neurological conditions.

Recommendation 1:
We recommend 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 mandated through the issuing of improved clarification and guidelines.

Trialling independent assessments

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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

In the development phase, the first pilot of 500 participants was limited to people with intellectual disability, psychosocial disability and autism. 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 the total number and range of participants (including disability, state/territory, age or gender) have not been confirmed.

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 remaining 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. The NAA 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.

Recommendation 2:
We recommend that the NDIA postpone the implementation of independent assessments until the second pilot can be completed, outcomes determined and corroborated with the first pilot report, and any revisions to the Framework considered.

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

No comment.

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

The NAA is concerned that the resources required to successfully implement independent assessments may not have been accurately determined by the NDIS.

The development and implementation of an effective NDIS plan requires a considerable level of specialised 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, usually on more than one occasion. This cannot be done within the timeframes anticipated in the Framework.

While it may appear 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 needing 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/neuromuscular conditions.

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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

Without the appropriate training and extensive experience of working with people with neurological and/or neuromuscular conditions, 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, or in some cases on the lack of insight into their condition of an individual being assessed.

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 its webpage the assessment will take "1-4 hours" which is unlikely to produce an accurate report if the assessor has little or no knowledge and experience of neurological/neuromuscular conditions. These conditions can affect all areas of a person's functions; it is demonstrably 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:
We recommend that the Framework be amended to require and 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 these conditions.

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

People with neurological/neuromuscular conditions 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.

Neurological/neuromuscular conditions are 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 one of these conditions, likely leading to a poor outcome for the participant and resulting in even more complaints and need for plan reviews.

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

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 choice and 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 both initially as applicants and as continuing participants, and negative consequences due to inadequate provision of disability supports, leading to overall disengagement with the NDIS. This may be of particular concern where significant barriers to access already exist, such as language or cultural factors for those from CALD backgrounds.

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 often 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 (progressive) disease journey.

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 the independent assessor cannot demonstrate that they have at least a basic understanding of the condition of the person they are assessing, specialist input must be required.

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 skyrocketed 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".

Recommendation 4:
The NAA strongly recommends that assessments are transparent, accountable and reviewable, allowing participants to appeal a decision or to provide further information as required to ensure their needs and goals are central to the application process.

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 people living with neurological and/or neuromuscular conditions, we are concerned about the impact of these assessments on the diverse communities served by the members of the NAA.

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 progressive, degenerative neurological and/or neuromuscular conditions are assessed by assessors with specialist knowledge and experience of working with people living with these conditions.

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 neurological and/or neuromuscular conditions, 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 neurological/neuromuscular conditions are 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 or other health crisis 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 hospitalised to 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 5:
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.

Ability to access higher levels of care in crisis situations

Those people living with those neurological conditions that cause them to move unpredictably in and out of crisis need to access higher levels of care (e.g. Level 3 support coordination) much more urgently than "change of circumstances" or "plan review" processes will ever allow. The Framework must ensure processes exist to cater for people needing urgent adjustments to higher levels of care in response to crisis situations.

Recommendation 6:
We recommend that the Framework include processes to meet the needs of people needing urgent adjustments to higher levels of care in response to crisis situations.

Neurological Alliance Australia
31 March 2021

For more information about the contents of this submission, please contact:

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The Neurological Alliance Australia *is an alliance of not-for-profit peak organisations representing adults and children living with progressive neurological or muscular diseases in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and funding to support research. Members of the Alliance include Dementia Australia, Brain Injury Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia, Spinal Muscular Atrophy Australia, Leukodystrophy Australia and Polio Australia.*