



**Carers Australia submission to the Joint
Standing Committee on the National
Disability Insurance Scheme inquiry:
*Independent Assessments***

31 March 2021

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Our vision is an Australia that values and supports the contribution that carers make both to the people they care for and to the community as a whole.

We believe all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

For information contact:

Ms Liz Callaghan
Chief Executive Officer
Carers Australia

Unit 2, 11 McKay Lane TURNER ACT 2612
Telephone: 02 6122 9900
Email: ceo@carersaustralia.com.au
Website: www.carersaustralia.com.au

Introduction

Carers Australia welcomes the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme (the Committee) inquiry into Independent Assessments. This submission considers and responds to the terms of reference particularly in relation to how the proposed Independent Assessments may impact carers of people with disability. The submission has been informed by the National Carer Network.

This submission responds to following terms of reference in particular:

- a. the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS;
- d. the independence, qualifications, training, expertise and quality assurance of assessors;
- e. the appropriateness of the assessment tools selected for use in independent assessments to determine plan funding;
- f. the implications of independent assessments for access to and eligibility for the NDIS;
- g. the implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports; and
- l. any other related matters.

Carers are people who provide unpaid personal care, support and assistance to family members and friends or other individuals who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. There are over 2.65 million carers in Australia, and more than 860,000 of those are primary carers, who provide the most informal support to a family member or friend. Around 1 in 11 carers (235,300 people) are under the age of 25.

Carers are an integral part of Australia's health system and are the foundation of our aged, disability, palliative and community care systems.

It is important that carers are supported to participate in economic, social and community life, as recognised by the *Statement for Australia's Carers* under the *Carer Recognition Act 2010* (the Act). The Act aims to increase recognition and awareness of carers and acknowledge the valuable social and economic contribution they make to society. The *Statement for Australia's Carers* states that all carers should have the same rights, choices and opportunities as other Australians, and that carers should be acknowledged as individuals with their own needs within and beyond the caring role.

Discussion

Evidence, reasons and justifications for the introduction of independent assessments

There appears to be three central policy aims or justifications underpinning the proposals around independent assessment:

1. Greater equity of access to the NDIS: removing barriers of cost and time to seek evidence of functional capacity;
2. Improve information and evidence for access and planning decisions, expected to lead to fairer and more consistent decisions; and

3. Improving consistency in funding levels for participants with similar levels of functional capacity and environments.

The Department of Social Services (DSS) describes the reforms as seeking to “improve the NDIS” and “make the NDIS fairer, with better information for decision making, at less cost for participants and those applying to become participants”¹.

However, Carers Australia, like other stakeholders, is concerned that the potential effects of Independent Assessments on participants’ budgets (at an individual level) and funding (at a scheme level) are not transparent. Government and the NDIA need to be transparent about the modelling and parameters it is proposing to accept around potential reductions in funding that might result from the Independent Assessments.

While the policy aims noted above are reasonable in themselves, Carers Australia is concerned that the Government and NDIA have not balanced consideration of these with the potential unintended, negative consequences the proposed changes could have on people with disability and their carers, as discussed further below.

Equity of access to the NDIS

Funded functional assessments as outlined in the NDIA’s consultation papers would not fully address inequities in access to the NDIS. On the basis of the consultation papers it appears functional assessments would be the second step or ‘gate’ through which participants would gain access to the scheme.

The first step – an initial Access Request with evidence of age, residence and disability – remains. Initial eligibility will continue to be determined ahead of the functional assessment and will continue to rely on families’ capacity to pay for appointments with health professionals and supporting material (i.e. evidence of disability and permanence) in order to qualify for access to the scheme. The proposed Independent Assessment process does not address this aspect of inequity of access to the scheme, nor does it address barriers those in regional and remote can face in accessing health professionals to seek this documentation.

The NDIA’s consultation papers also do not address the issue raised by some stakeholders about how functional assessments will be equitable for those people with disability whose functional capacity may be episodic or vary day-to-day (e.g. mental health), where the assessment is not conducted on a representative day, and where carers are likely to have additional knowledge about the impact of mental health on the participant.

Fairer and more consistent decision-making

Carers Australia recognises that the use of functional assessments using standardised tools could improve consistency in decision-making. However, it is important to remember the principle – central to the human rights model of disability – that people with disability are experts in their own lives and in their own experience of living with disability. Government must be careful to use standardised tools and functional assessments in a way that stays true to this principle.

Carers Australia also questions whether such functional assessments must by default be carried out by ‘independent’ assessors. There does not appear to be sufficient evidence against enabling participants’ or potential participants’ treating practitioners to complete the functional capacity assessments using standardised tools. High quality and consistent information could still be achieved with the use of standardised tools, while still enabling participants and prospective participants to seek functional assessments from treating practitioners. This would address concerns expressed by some disability organisations and advocates about the ability of an assessor unfamiliar with the person with disability to build a complete and accurate understanding of their functional ability, and the potential harmful effects for people with disability with a history of trauma, abuse or violence.

¹ DSS website, accessed 5 January 2021.

As the Committee has noted, while the Tune Review and Productivity Commission expressed qualified support for functional capacity assessments it is not clear that they recommended mandatory independent assessments in the model proposed by the NDIA.² The Tune Review recommended the NDIA be provided discretionary powers to require a prospective participant or participant to undergo an assessment; **it did not** recommend that independent assessments be mandatory.³ As the Committee has observed, it is not clear that the data obtained through the pilots was sufficient to support introduction of independent assessments as a compulsory part of the NDIS access and planning processes.⁴

As the Committee is aware, Mr David Tune AO PSM also raised other issues, which were not sufficiently addressed in the NDIA's consultation papers:

- that a panel of assessors would need to have sufficient depth to mitigate engagement risks e.g. with specific cohorts such as Aboriginal and Torres Strait Islanders, those from culturally and linguistically diverse (CALD) backgrounds, and those with psychosocial disability;
- it may not always be possible to source an appropriate provider, or there may be circumstances where it is more appropriate for non-approved providers to undertake the assessment; and
- a functional capacity assessment itself may not always be required (e.g. if a participant's functional capacity is stable)⁵.

Carers Australia acknowledges that in some cases there may be the potential for conflict of interest where a person's NDIS provider or treating practitioner is completing the functional assessment. However, there are other ways to address this than mandating independent assessments across the board (which would require a new workforce and is likely more expensive than other options). More importantly, the NDIA has provided little evidence of the prevalence of 'sympathy bias' and nor has it quantified the impact (that is, the degree to which any bias inflates or deflates participants' funding levels).

The NDIA could instead pursue greater transparency in decision-making and expected funding levels. For example, the risk of inflated functional assessments could be mitigated if the NDIA published benchmark pricing/funding for the 'typical support packages' it uses in planning decisions,⁶ to both improve transparency of NDIA decision-making, but also to provide a framework for discretionary independent assessments where a functional assessment undertaken by a provider or treating practitioner fell outside the expected range. A panel of independent assessors could in this case be called on to review the results of a functional assessment and undertake a new one if necessary.

In this way, a panel of independent assessors could exist for these review situations and for participants and prospective participants to use if needed. The requirement to undertake an independent assessment would be a discretionary power, not the default, which reflects Mr Tune's recommendation. This would balance the policy objectives, the need to ensure a complete and accurate understanding of individual needs, while introducing appropriate rigour

² Joint Standing Committee on the NDIS, *General issues around the implementation and performance of the NDIS*, December 2020 report, p. 42.

https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_issues/Interim_Report

³ David Tune, *Review of the NDIS Act report*, p. 67. <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-insurance-scheme/review-of-the-ndis-act-report> Tune also acknowledges that a functional capacity assessment itself may not always be required (e.g. if a participant's functional capacity is stable).

⁴ Joint Standing Committee on the NDIS, *General issues around the implementation and performance of the NDIS*, December 2020 report, p. 42.

https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/General_issues/Interim_Report

⁵ Tune, *Review of the NDIS Act report*, p. 67.

⁶ See Tune, *Review of the NDIS Act report*, pp. 64-65.

around use of public funds and incentivising providers and health practitioners undertaking functional assessments to do them as objectively and accurately as possible.

The role of carers and informal supports (and ‘reasonable and necessary’ supports)

Informal supports are the help and support provided by unpaid carers, family or friends (for example, physical and personal care such as dressing and feeding, medication management, and emotional and social support).

According to the NDIA’s current Operational Guideline 9 – The statement of participant supports, a participant’s plan must include a statement of participant supports, prepared with the participant and approved by the NDIA, that specifies the ‘general supports’ that will be provided to the participant and the ‘reasonable and necessary supports’ that will be funded under the NDIS⁷. General supports are services or activities undertaken by the NDIA (e.g. the allocation of a Local Area Co-Ordinator). Reasonable and necessary supports are those specified in a participant’s plan that are funded by the NDIS and which “help a participant reach their goals, objectives and aspirations, and to undertake activities to enable the participant’s social and economic participation”.

In determining which supports are reasonable and necessary (and the requisite level of funding), the NDIA examines what supports are already being provided, or “should reasonably be provided” by informal supports (and community and mainstream supports)⁸.

How will functional assessment capture the roles, sometimes invisible, of carers, and how will this impact budgets?

There is little in the information and consultation papers about the role of carers in relation to Independent Assessments, or about how carers will be factored into functional assessments. It appears that carers will continue to be included only insofar as they provide informal supports to the person with disability. Carers will not be assessed in their own right; that is, in terms of their capacity to provide care, or in terms of the supports they might need.

The stated intention is to improve consistency of funding levels for participants with the same or similar levels of functional capacity, including the impact of their environment. It is unclear, however, whether and to what extent funding levels will vary depending on the informal supports available to different individuals. The *Planning Policy for Personalised Budgets and Plan Flexibility* consultation paper states that the budget will reflect the expected costs of providing a reasonable and necessary package of supports for a participant with “a similar level of functional capacity, support need and environmental context”⁹. Further clarity is needed about how informal supports will be assessed, and how this will impact draft budgets.

How would independent assessments impact and consider the perspectives of carers?

NDIA funding of functional assessments would reduce the cost, time and effort required for prospective participants and their families and carers to seek and provide reports, letters and assessments required to provide evidence to request access to the scheme (noting that it would not address the inequities in making initial Access Requests).

Under current arrangements carers are able to complete a carer statement (or Impact Statement) outlining their role and how that role impacts them, as well as how the NDIS Plan can ‘sustain capacity to care’. Noting that there is currently no requirement for these statements to be considered in NDIS access, budget and planning decisions (and carers may not be aware of them in the first place), it is also unclear from the consultation papers

⁷ NDIS, “Planning Operational Guideline – The statement of participant supports” <<https://www.ndis.gov.au/about-us/operational-guidelines/planning-operational-guideline/planning-operational-guideline-statement-participant-supports>> [accessed 10 March 2021].

⁸ NDIS, “Planning Operational Guideline – The statement of participant supports”

⁹ S 9.3 “Interaction between informal / mainstream supports and reasonable and necessary supports”

⁹ National Disability Insurance Agency, *Consultation paper: Planning Policy for Personalised Budgets and Plan Flexibility*, p. 13.

released whether or how such statements would be considered as part of the functional assessment, or budget and planning decisions.

The NDIS website acknowledges that “Families and carers provide help and support that could otherwise be provided by formal services or paid support workers” and that “an NDIS participant might use funding in their plan to facilitate respite. Respite supports participants and their carers by giving carers short breaks from their caring responsibilities. It also gives participants time away from their families”¹⁰. This illustrates the need to have informal supports/carer capacity assessed in its own right: this will enable better budget and planning decisions to better sustain caring relationships, as well as improving policy alignment with the object of the *Carer Recognition Act 2010* and *Statement for Australia’s Carers*.

While the eligibility and assessment process for access to the NDIS – including proposed functional assessments – will principally inform decision making for NDIS funding and services provided to the person with disability, these decisions can also impact carers. That is, the extent to which carers are relied on to continue to provide any informal care and supports provided at the time of assessment can have significant consequences for the health and wellbeing of the carer, the sustainability of the caring relationship, but also other aspects of carers’ lives, such as social and economic participation.

There are only limited references to carer perspectives in the *Independent Assessment Framework*, which suggests that carer perspectives may only be sought in the context of additional information that may be needed to “acknowledge the complexity of disability and humanity”¹¹. While the framework states that this assessment approach will “inform decision making and assist NDIS delegates by providing a holistic profile of each person’s function”¹², stakeholders will need to see draft legislation and guidance documents to fully understand how such perspectives would be considered. It is clear, however, that such information would be seen by the NDIA as optional and supplementary and not a core part of the assessment.

The NDIA needs to further consider how the requirement to repeatedly tell their stories or speak about their experiences might be stressful or traumatic for carers, as other stakeholders have pointed out may be the case for some people with disability. This can be exacerbated where the person is unfamiliar with the health professional, or where they feel they have little control or choice in the process. The NDIA must remember that people with disability and their carers are required to tell their stories or be assessed repeatedly through the journey to diagnosis and accessing supports.

‘Reasonable’ and ‘normal’ supports

The consultation papers released so far do not address the issue (previously identified in Carers Australia’s submission of October 2019 to the Department of Social Services Discussion Paper on the NDIS Experience¹³), of the need for greater clarity around ‘reasonable’ or ‘normal’ supports that families and carers can be expected to provide.

According to 10.7 of the Planning Operational Guideline¹⁴ for an adult participant these considerations include the suitability of family members, carers, informal networks and the community to provide the supports, considering factors such as:

¹⁰ NDIS website – ‘How we can help carers’ webpage [accessed 18/1/21]

<https://www.ndis.gov.au/understanding/families-and-carers/how-we-can-help-carers>

¹¹ National Disability Insurance Agency, *Independent Assessment Framework*, August 2020, p. 24.

¹² *Independent Assessment Framework*, p. 24.

¹³ See ‘Submission to the Department of Social Services Discussion Paper on the *NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape*’ especially pp. 10-12. Available on the Carers Australia website <<https://www.carersaustralia.com.au/submissions-reports/submissions/>>

¹⁴ NDIS website, ‘Planning Operational Guideline – Deciding to include supports in a participant’s plan’ <<https://www.ndis.gov.au/about-us/operational-guidelines/planning-operational-guideline/planning-operational-guideline-deciding-include-supports-participants-plan#10.7>> accessed 18 January 2021.

- the age and capacity of family members and carers and extent of supports to sustain them in their caring role;
- intensity and type of support required, and gender and age appropriateness; and
- any risks to the long-term wellbeing of any of the family members or carers.

The Guideline also states: “The community has general expectations about the supports which could be reasonably provided by family or primary care givers. The NDIS may fund supports that are needed as a direct result of a participant’s disability, but is not intended to displace the ordinary role of parents, families and carers”¹⁵.

As part 11 of the Guideline recognises, “Support loads and other factors such as illness or ageing can place a carer’s wellbeing at risk and compromise their capacity to continue in their caring role. Accordingly, the NDIA recognises that sustaining these informal supports can often be an integral component of meeting a participant’s needs”¹⁶.

Carers Australia is concerned about the lack of information about how a standardised functional assessment process would assess and determine what informal supports are ‘reasonable’ and ‘normal’ for carers and family members to provide, noting this can be subjective and value-driven. Carers Australia urges the Committee to consider and the NDIA to clarify its proposed approach to assessment, decision-making processes and degree of discretion delegates will have in this regard.

Recommendations

Carers Australia supports the policy aims in-principle. That is, Carers Australia supports **in-principle** government-funded functional capacity assessments using evidence-based, standardised tools. However, Carers Australia has urged the NDIA to revisit aspects of the proposed policy, trial different approaches to achieving the policy aims, evaluate and publish the outcomes of different approaches. In our view, the policy aims could be achieved without mandating the assessments be undertaken by an ‘independent’ assessor.

In Carers Australia’s view:

- There does not appear to be sufficient evidence against allowing participants’ or potential participants’ treating practitioners to complete the functional capacity assessments using standardised tools, if some oversight mechanism is introduced. The use of standardised tools to assess functional capacity would still provide the information and evidence needed for access and planning decisions.
- Equity in assessment could still be achieved if the NDIA makes a panel of independent assessors available (e.g. if preferred by participants, or if required to validate an assessment undertaken by treating practitioners) and funds functional capacity assessments regardless of whether a panel provider or participant’s treating practitioner undertakes the assessment.
- The NDIA should trial, evaluate and publish outcomes of different approaches, e.g. functional capacity assessments using standardised tools carried out by a person’s treating practitioner/s, but still funded by NDIA.
- The NDIA should clarify the relationship between functional assessments and initial steps toward access and eligibility for the NDIS.

¹⁵ NDIS website, ‘Planning Operational Guideline – Deciding to include supports in a participant’s plan’ <<https://www.ndis.gov.au/about-us/operational-guidelines/planning-operational-guideline/planning-operational-guideline-deciding-include-supports-participants-plan#10.7>> accessed 18 January 2021.

¹⁶ NDIS website, ‘Including Specific Types of Supports in Plans Operational Guideline - Sustaining informal supports’ <<https://www.ndis.gov.au/about-us/operational-guidelines/including-specific-types-supports-plans-operational-guideline/including-specific-types-supports-plans-operational-guideline-sustaining-informal-supports#11>> accessed 18 January 2021.

- The NDIA should clarify participants' review or appeal rights around the results of a functional capacity assessment undertaken by an independent assessor.
- The NDIA should consider options to address remaining inequities in access to the NDIS, including the cost of obtaining evidence of permanent disability.

It is important that carers are supported to participate in economic, social and community life, as recognised by the *Statement for Australia's Carers* under the *Carer Recognition Act 2010*. For this reason, carers need to be considered in assessment processes in their own right.

- Functional assessments for NDIS participants should include a separate assessment for carers which reflect their needs for support in their own right (including respite) and referral to services which cater for such supports, rather than just a consideration of their stress levels in the context of the services and supports which need to be included in the participant's NDIS budget and plan, and ongoing sustainability of the caring relationship.
- A standard-form Carer Statement or Impact Statement should be used as a compulsory component of assessment to provide a more accurate picture of the everyday barriers experienced by the individual and their family, and to verify how much care and support an individual may need. This would support the NDIA's policy intention to improve consistency of information and decision-making, and if collected appropriately contribute to better data about the informal care provided to people with disability (and carer policy in general). This should then be integrated into the referral pathway for Carer Gateway services.

Draft legislation

Carers Australia, like other organisations in the disability sector, carers, parents and people with disability, is concerned about the apparent consideration being given to reductions in access to the NDIS by some participants, such people with acquired brain injuries and fetal alcohol spectrum disorder, which has been reported in recent media. Carers Australia urges Government to release the draft legislation for proper community consultation.