



Submission from the NSW Carers Advisory Council

The NSW Carers Advisory Council writes to you in regards to the Terms of Reference for the Parliamentary inquiry into independent assessments under the NDIS.

The Council provides advice to the NSW Government on legislation, policy and other matters relating to carers. For more information about the Council and its members, the majority of whom are carers, please visit the Council website:

<https://www.facs.nsw.gov.au/inclusion/advisory-councils/carers>

The Council provides feedback on the Terms of Reference in the table below, but in addition to those concerns, also notes:

- The first pilot indicated that 91% of those who received an independent assessment were satisfied or very satisfied. Council is extremely concerned at this response as it seems that only 28% of all who received an independent assessment responded to the evaluation survey. The data also does not indicate whether the participants completing the evaluation survey include carers in addition to people with a disability. Council would prefer to see a higher level of confidence in the independent assessment with increased numbers of responses providing greater statistical reliability.
- Council is concerned that while it is good that *"Independent assessments will be done by trained experts, for example occupational therapists, physiotherapists, psychologists and other health and allied health professionals"*, this will exacerbate the shortage of allied health professionals, particularly in regional and remote areas. If a large number take up the role of independent assessors they will not be available to provide hands-on support for clients or even worse, there would be a conflict of interest if they attempt to do both. If there is less allied health support available, the workload for carers increases.

Following are the Council's responses to the Terms of Reference:

Terms of Reference	Comment
a) the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS;	Among the information that will be needed are the following: <ul style="list-style-type: none">• That the assessors are experienced, skilled and have received an appropriate level of training in the assessments.• That (as proposed by the NDIA) the psychosocial assessments are done by self-nominating assessors who have lived experience or specific skills with this target group.• Information should be developed that is targeted to both potential participants and their carers.• Clear information about eligibility is also needed – for all groups of people (disability, psychosocial and chronic, acute or palliative health conditions).

<p>b) the impact of similar policies in other jurisdictions and in the provision of other government services;</p>	
<p>c) the human and financial resources needed to effectively implement independent assessments</p>	<ul style="list-style-type: none"> • There should be adequate planning for the number of assessors and trained experts required within each region to minimise the loss of services due to conflicts of interests and to ensure there are enough trained experts to spend sufficient time on each assessment. • There should be sufficient notice given to participants and carers about upcoming changes to the NDIS processes. The amount of change and frequency of change has made accessing the NDIS difficult. Communications about process changes should be made at least 6 months prior to the change occurring with clear guidelines about the impacts on participants and carers. Previous changes have been made with 1-2 months' notice (e.g. price guide changes) and this has caused distress for participants, carers and service providers.
<p>d) the independence, qualifications, training, expertise and quality assurance of assessors;</p>	<ul style="list-style-type: none"> • The independent assessors must be sympathetic to carers who are under undue stress, and that they understand trauma-informed practice so that carers are not penalised for their advocacy. • Other desirable skills of assessors should include: <ul style="list-style-type: none"> ➤ Empathy ➤ Lived experience ➤ Training ➤ Understanding of the assessments they are giving ➤ Acknowledging the families and carers as holders of key information ➤ Acknowledging that sometimes the person with a disability does not know or understand the needs of their carer. ➤ Cultural respect - the independent assessment needs to understand and respect the CALD community as there are different cultural customs in many different CALD communities and this needs to be understood and accommodated. ➤ Cultural respect for caring in Aboriginal communities ➤ Cultural capability training ➤ Be from diverse cultural backgrounds ➤ Diverse cultural backgrounds
<p>e) the appropriateness of the assessment tools selected for use in independent assessments to determine plan funding</p>	<ul style="list-style-type: none"> • The Independent Assessment pilot learnings and ongoing evaluation plan available on the NDIS website details the assessment instruments and who should complete them (in Appendix A on pp 20-22). Council has reported that this acknowledges the important role of the carer and their expertise about the participant, and implies they will have a prominent role in assessment. However, the role of carers in the assessment process is not addressed in sufficient detail elsewhere by the NDIA. The amount of time that carers will need to put aside to provide the information is significant,

	<p>depending on the instruments used, and the information from the NDIA should better explain, reflect and recognise this. Without further information about how carers will be engaged as a critical part of this process, it will not happen or it may not work. Critically, it appears that none of the instruments being used in the IA will actually ask anything about carers' own needs and capacities.</p>
<p>f) the implications of independent assessments for access to and eligibility for the NDIS</p>	<ul style="list-style-type: none"> • The NDIA consultation paper: Access and Eligibility Policy with Independent assessments" on page 9 (2.2.2) outlines in S 2.2.2 the steps that will be undertaken for people to enter into the NDIS. It indicates there will "also be clearer guidance for all applicants on what defines a permanent disability requiring support under the NDIS. This guidance will: <ul style="list-style-type: none"> ○ outline what we need from medical professionals to understand the permanence of a person's disability ○ provide detail on the most appropriate treatment system for health conditions ○ clearly deal with the issues arising from the functional capacity impacts of chronic, acute and terminal health conditions." • This is a critical consideration for Council. Council is concerned that some groups of people with chronic illness are missing out on the NDIS as the impact of their health conditions on their functional capacity is not being appropriately assessed. This is increasing demands on carers' time, responsibilities and finances, and negatively impacting on the health of some people with chronic illness who may not be able to afford ongoing therapies critical to their wellbeing without NDIS support. • Current research being undertaken by the NSW Carers Advisory Council provide real examples of this. Data provided by the main community organisation assisting people with cystic fibrosis in NSW (Cystic Fibrosis Community Care, CFCC) shows that less than 13 % of individuals with Cystic Fibrosis assisted by CFCC to apply for the NDIS, were successful. They or their carers are now frequently having to directly fund daily physiotherapy services for lung clearance, at significant expense (or the carer is struggling to provide the physiotherapy themselves). These services were previously available and subsidised under Home Care. • Council also considers that the most important thing to identify is the impact of a person's disability on their core functions, NOT the cause of their disability. It does not matter if the cause of an individual's disability is a chronic health condition or another disability, provided this results in a significant adverse impact on an individual's core functioning capacity eg their capacity to communicate, to participate in community life and/or their mobility. This impact may be constant and continuous or may fluctuate over time due to acute episodes of an acute illness or disability. • During a person's lifetime they may have different needs. E.g. it may be discovered that you have Autism Spectrum Disorder 2 which requires OT support, so you might then need an assessment. As you age, issues may further develop around

	<p>your speech which has become harder to understand so you need Speech therapy. All of these will change your plan.</p> <ul style="list-style-type: none"> • Access to and eligibility for the NDIS relies heavily on 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. • NDIS created new terms and language that are not in common use outside of NDIS. This can result in evidence, for example provided by doctors, not being written in language that complies with NDIS evidence, despite the evidence clearly demonstrating the disability and permanent and life-long impact. • The evidence they are required to provide should be easy to complete and straightforward and if not written in NDIS language, this should not affect access to and eligibility for the NDIS. • The episodic nature of some psychosocial disabilities can make it difficult to assess needs with a one-off assessment depending on the mental health of the person at the time of the assessment.
<p>g) the implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports</p>	<ul style="list-style-type: none"> • It appears that the functional assessment process will determine the amount of money allocated to a person's plan. This will happen before any planning meeting. It seems that plans will now need to fit into the allocated budget rather than determining a budget to fit in with a plan. • The document "Plan flexibility and budget planning" states "Your independent assessment will be an important part of your plan, and will change how we build your personalised plan budget. Instead of creating a plan that has funding based on individual items or supports, your budget will be closely matched to your functional capacity and the impact of your environment, based on the information in your independent assessment". This is a significant shift in the intent of the NDIS where funding should be linked to the person's support needs that are reasonable and necessary. There are other aspects to a person's life other than a functional assessment that may need to be considered when looking at their support needs. • Council is very concerned that the independent assessment does not formally take into account the amount of informal support that the carer is able (or willing) to provide.
<p>h) the circumstances in which a person may not be required to complete an independent assessment</p>	<ul style="list-style-type: none"> • Someone with a very severe life time disability should not have to go through unnecessary, costly and potentially stressful additional assessments once they've been approved for Disability Support Pension. The main thing that should prompt an additional assessment would be advice from the care recipient or carer that the needs of the person with a disability have changed. • A carer's comment: "I was wondering about the Disability Support Pensions and the Independent Assessments. I know that when my son was eligible to apply for the DSP - I was told he would never have to be assessed again due to the severity of the disability. Surely, this can also be the approach of the NDIA and possibly the assessment done by one Govt agency

	<p>(Centrelink) should be applicable to other Govt agencies. I know this only means it is applicable for people of a certain age and perhaps a certain severity but it could be worth progressing as a thought.”</p> <ul style="list-style-type: none"> • There should be exceptions to the IA process for known disability types that have demonstrated history of severe complex disability.
<p>i) opportunities to review or challenge the outcomes of independent assessments</p>	<ul style="list-style-type: none"> • The IA consultation paper on page 23 states that “Independent assessment results themselves will not be directly reviewable by the AAT Disagreeing with the results of an otherwise sound and robust independent assessment is not sufficient for the NDIA to fund another assessment. Applicants can only seek a second assessment where the assessment was not consistent with the independent assessment framework, or if the applicant has had a significant change to their functional capacity or circumstances.” • The Council is concerned that this will put carers in a very difficult position if they feel that the IA process does not reflect the actual situation for the person with the disability or their role as the carer. It is fair and reasonable that there is a mechanism for a carer or the person with a disability to request a review.
<p>j) 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</p>	<ul style="list-style-type: none"> • Ways to promote cultural safety and inclusion include: <ul style="list-style-type: none"> ➢ Codesign with young Aboriginal people who have psychosocial disabilities ➢ Co-design with people from regional, rural and remote areas ➢ Codesign with LGBTIQ+ community ➢ Codesign with CALD community ➢ Train all staff - not just once but often ➢ Employ assessors and trained experts from diverse cultural backgrounds ➢ Ensure interpreters are readily available to be part of the IA process
<p>k) the appropriateness of independent assessments for people with particular disability types, including psychosocial disability</p>	<ul style="list-style-type: none"> • Carers of people with psycho-social conditions know that it takes time and multiple visits to develop trust between a client and professional. A one off assessment by a stranger who does not know a person will not be comprehensive or elicit the necessary information. People with psycho-social conditions also sometimes exclude their carers from assessments. Appropriate guidelines are required to support these carers, and skilled assessors. • It has been mentioned that in the proposed process phone assessments will be an option of undergoing an Independent Assessment. Council believes that phone assessments may not easily accommodate carer input. Phone planning meetings were discontinued by NDIA as they were not satisfactory. Phone planning meetings are currently still occurring for NDIS plan reviews more broadly - these are not adequate for a local area coordinator or assessor to understand a person's disability. In-person planning meetings or at a minimum a video call meeting would be better suited.

	<ul style="list-style-type: none"> • Information regarding IA timeframes must be well defined with a service guarantee and must include all these stages: • turnaround waiting time for an assessment appointment; • actual time to have the assessment and report completed; and when the NDIS and potential participant and family are notified of the outcome. • We are aware of a positive experience of a carer involved in the IA pilot. They reported a positive experience with being assessed at home “We did our pilot via Telehealth with the camera off till (daughter) felt safe. He wasn’t in her space. And she could stay home. Was good for her.”
l) Any other related matters	<ul style="list-style-type: none"> • The needs of carers change as they age and this needs to be considered in relation to IA. As carers age their capacity to care for their adult children with disabilities decreases, so more support is needed to mitigate this decline in carer ability. This can result in a significant plan change, but not one that is driven by changes in the participant’s needs.

On behalf of the NSW Carers Advisory Council and carers across NSW, I ask that you review our feedback taking into consideration needs and the role of carers. We also give permission for our submission to be published.

If you wish to discuss this further, I can be contacted on Ph: 0408 020 904 or at NSWCarersAdvisoryCouncilSecretariat@facs.nsw.gov.au

Yours Sincerely



Prue Warrilow
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