



**CRE-DH**

Centre of  
Research Excellence in  
Disability and Health



# SUBMISSION ON THE NATIONAL DISABILITY INSURANCE SCHEME'S INQUIRY INTO INDEPENDENT ASSESSMENTS

in partnership with



## About the submission

This submission is made on behalf of researchers from the Centre of Research Excellence in Disability and Health (CRE-DH) funded by the National Health and Medical Research Council, 7 April 2021.

## About the CRE-DH

The Centre of Research Excellence in Disability and Health (CRE-DH) aims to identify cost-effective policies to improve the health of people with disabilities in Australia. There are four interconnected research areas in the CRE-DH focused on:

1. mapping the health inequities between Australians with and without disabilities,
2. analysing the social, economic and environmental factors that contribute to the poorer health of people with disabilities,
3. modelling the cost-effectiveness of health policy interventions, and
4. policy analysis and reform.

The CRE-DH is funded by the National Health and Medical Research Council. We are an interdisciplinary research group comprised of academics from five universities, a team of international advisors and a Partner Advisory Group of stakeholders from the disability and health sectors. The CRE-DH Co-Directors are Professor Anne Kavanagh (University of Melbourne) and Professor Gwynnyth Llewellyn (University of Sydney). The CRE-DH includes Chief Investigators from the University of Melbourne, University of Sydney, Monash University, UNSW Canberra and RMIT with multidisciplinary skills in epidemiology, health economics, health and social policy, psychology, psychiatry, public administration and public health. In addition, we have Associate Investigators from a range of national and international universities and the World Health Organization. We work in collaboration with key stakeholders including DSS, ABS, AIHW and peak bodies in the disability advocacy and service sector through our Partner Advisory Group. Several members of the CRE-DH research team and the Partner Advisory Group also have lived experience of disability.

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# Submission to the Joint Standing Committee on the National Disability Insurance Scheme's Inquiry into Independent Assessments

Our submission to the committee comments on issues in relation to a range of the terms of references outlined for this inquiry. We are concerned that the introduction of Independent Assessments (IAs) will be damaging to current and potential NDIS participants and the 'consultation' process on this policy has not been consistent with the core principles of the scheme including co-design and choice and control. IAs have been justified on the basis that they will lead to consistency and therefore be more equitable, concentrate function rather than medical diagnosis, and Scheme sustainability. We believe that they fail on all these objectives and that their use will exacerbate inequities in practice.

Against this background we are calling for:

- A halt to the implementation of IAs
- A commitment to release pilot data collected to date including how they were used to determine funding outcomes
- A commitment to co-produce any future functional assessment component of the scheme and its evaluation with people with disability and other stakeholders with expertise in the area including academics and allied health professionals
- A commitment to rigorous evaluation of functional assessments against their purpose of allocation of budgets for reasonable and necessary supports that meet participants' goals
- A commitment to not use functional assessments as the sole (or main) basis of funding decisions
- A commitment to determining 'reasonable and necessary' support on the basis of individual goals
- A commitment to promoting equity through investment in advocacy and development of culturally appropriate services in areas of need.

## **ToR 1: The development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS**

A number of justifications for IAs have been made. These include that: a) that they appear in the original Productivity Commission report and the Tune review; b) lead to consistency and therefore are more equitable; c) they take the environment into account; d) they concentrate on function rather than medical diagnosis, and e) they will support Scheme sustainability.

### **a) Productivity Commission report and Tune Review**

The blueprint for the NDIS, created by the Productivity Commission (PC)<sup>(1)</sup>, has been used by the CEO of the NDIA to support the use of IAs. We contend this is a misreading of the document. The PC said assessors should be independent (e.g., health professionals and allied health care workers, not government contracted professionals). The concern for standardisation in the PC design was not with assessment, but rather what follows. That is, once materials had been collected by potential participants the *process of assessing* these reports is standardised.

The clause within the PC blueprint used to justify IAs similarly covers all medical professionals already providing reports for NDIS participants. At present, applicants submit evidence from medical professionals and specialists. The CEO of the NDIA has stated in his submission to the JSC that these professionals may have 'sympathy bias'<sup>(2)</sup>, while IAs will not. There is no reason to think that these highly trained professionals have a 'sympathy bias' and are not independent. One could argue, in fact, they are more independent than a contractor working for the NDIA who feels accountable to that body and not people with disability.

Similarly, the CEO of the NDIA uses the Tune Review<sup>(3)</sup> to support the use of IAs stating that the review reinforced the importance of implementing more equitable assessments to support consistency in decision making. We return to the issue of equity and consistency below, but here simply note that the process surrounding the assessments proposed in the Tune Review differ from those being suggested in the current reforms in some important ways. Specifically, there is: a lack of co-design and proper consultation; a lack of discretion in independent assessments to ensure they are consistent with the NDIS Act; and, a lack of protections such as a participant's right to challenge assessment results. These aspects are crucial in ensuring that this process operates as an effective functional assessment and not simply as a cost-cutting measure. Further, release of the draft Tune Review report, accessed under Freedom of Information, suggests that the chapter on IAs was not part of the report authored by Tune, but inserted by the Commonwealth government.

### **b) Consistency and equity**

Minister Robert has argued that the introduction of IAs will make the process of applying to the NDIS and receiving a plan, "simpler, fairer and more consistent for participants, and their families and carers"<sup>(4)</sup>. While we would not disagree that the NDIS has a number of



inequities within it (see, for example, <sup>5, 6, 7</sup>), we do not believe the picture is as simple as has been portrayed in the media by the Minister where he has compared different urban and regional and rural areas in terms of plan size<sup>(4)</sup>, when there are many reasons why we might see these differences such as people with more complex disabilities moving closer to services and concentration of high-intensity supports such as Supported Independent Living in these areas. The statistics that are currently being presented are misleading and do not compare 'like with like'. **We urge the JSC to look into this more carefully before accepting these arguments at face value.** The critical issue may not be plan size, but utilisation of plans which requires a much different response than IA – it is about improving access to services and empowerment of participants to use them. The latest data from the NDIA shows for example, the average utilisation rate for East Arnhem is just 33%<sup>(8)</sup>. While there are a range of good reasons why utilisation rates will likely never be 100%, there are a significant proportion of areas within the country where these rates hover around the 60-70% mark. This shows that even if allocated budgets there are significant inequities in the ability to spend these. It is also possible that IAs are likely to favour those who know how to present their case to a government contracted official and operate within a specific administrative framework<sup>(9)</sup>.

While on face value consistency might seem fair, there are major problems with this approach. **Consistency** is defined as the ability to get close conformity across different population groups (e.g., across different ethnic groups)<sup>(10)</sup> when using instruments such as those proposed by the NDIA. It is unknown at the moment whether functional assessments meet this criterion although given what is known about use of instruments such as these in other contexts it is unlikely to be the case. (See ToR 5 on the appropriateness of the tools and ToR 10 on appropriateness across different groups for further elaboration on these critical issues).

### c) Environment and functioning

One of the major arguments the NDIA have put forward for these instruments is that they are consistent with the internationally accepted framework for conceptualising disability – the WHO International Classification for Functioning, Health and Disability (ICF)<sup>(11)</sup>. The ICF shifts thinking about disability away from medical diagnoses to functioning. However, it is not at all clear how the NDIA is using the selected tools to capture the ICF domains (e.g., body functions and structures; activity; and participation – referred to as functioning), as well as contextual factors including personal and environmental factors. As the tools were not designed with the ICF in mind it is difficult to see how they can be used to capture the ICF components. In particular, it is not clear how the environment will be assessed.

### d) Scheme sustainability

Given that IAs are driven, at least in part, over concerns

about scheme costs, IAs may seek to exclude individuals from the Scheme or particular supports or award smaller funding plans. However, while this *might* reduce scheme costs, it will likely result in increased costs in other areas of government spending, e.g., health, education, welfare. These unintended consequences and costs have not been assessed.

## ToR 2: The impact of similar policies in other jurisdictions and in the provision of other government services

It is of note that there is no other disability system in the world that adopts such an approach. This is, in part, a result of the fact that there are no tools (or suite of tools) that are accurate across all groups that have been designed for this purpose. The only analogous processes that we have been able to identify in our research are the processes that have been taken around the world designed to move individuals off benefits such as the Disability Support Pension. We only need look at experiences in the UK or the US to see that functional analyses linked to benefits has caused extreme psychological distress for individuals and led to a large amount of preventable harm<sup>(12, 13)</sup>.

## ToR 3: The human and financial resources needed to effectively implement independent assessments

The case has been made that the use of IAs will cut down on the costs for participants and their families in gaining access to the scheme. It is true that at the moment there can be significant costs incurred in gaining evidence from clinical professionals to prove eligibility for the scheme. But, the introduction of IAs does not remove this need. Prospective applicants will still need to prove their eligibility for the scheme *before* they will be referred for an IA. While the system will remove the need for gaining functional assessments, potential participants will still need to gain medical/clinical evidence within the new system to demonstrate they meet eligibility criteria, and this may be potentially *more* onerous for those who currently have impairments included on access lists that will disappear with the introduction of the new system. If the concern is about the costs borne by some in accessing the Scheme, then there are a range of alternatives that might be introduced such as a new Medicare item for assessment purposes.

There will be considerable human and financial resources needed to effectively implement these tools. At present much of the functional assessment work is gained by individuals either through paying professionals to undertake this work or receiving this through services paid for by other parts of government (e.g., health). This will significantly increase costs to the scheme, as we have seen in the maximum amounts of money slated for the organisations contracted to deliver IAs. It is also important to note that the professionals undertaking these

assessments are allied health workers and there is already a well-documented shortage of these workers within the system.

#### **ToR 4: The independence, qualifications, training, expertise and quality assurance of assessors**

The NDIA propose to use allied health professionals to do these assessments however it is not necessary for the allied health professional to be specialised in the area which the assessment is focussed. For example, a physiotherapist may administer the Vineland or a psychologist the Lower Extremity Function Scale. Many of the instruments are designed to be undertaken by clinicians specialised in the field. We are aware that participants and families who have already undertaken these assessments have indicated how underqualified many assessors were to assess functioning in areas outside their expertise (e.g., physiotherapist assessing speech). There are no quality assurance processes in place where performance of individual assessors is assessed. Given the lack of an appeals process, there is no recourse if an assessor makes inaccurate assessments. Furthermore, participants report the dismissal of information on functioning provided by the person with disability or families and carers and that data is collected from observation with little understanding of how the functioning is influenced by the environment (e.g., home, community).

#### **ToR 5: The appropriateness of the assessment tools selected for use in independent assessments to determine plan funding**

We have serious concerns about the tools that have been selected, the process for selecting them, and the evaluation conducted by the NDIA.

##### *a) Selection of tools*

The NDIA's report on the development of IFAs and selection of tools acknowledged there was no single tool that could be used as the basis for funding decisions<sup>(14)</sup>. Therefore, they decide to look at tools available 'off the shelf' i.e., *designed for another purpose* (e.g., LEFS – clinical tool for monitoring of progress in rehabilitation) and look at whether they cover the areas they need and whether they have good psychometric properties (i.e., reliability, validity). While the tools may have good psychometric properties for the purpose for which they were designed this does not mean they are suitable for the purpose the NDIA is using them for.

The NDIA argue that the chosen tools are reliable.

**Reliability** refers to "the degree to which the results obtained by a measurement procedure can be replicated"<sup>(10)</sup>. Lack of reliability may arise from differences between observers or instruments of measurement or instability of the attribute being measured. The NDIA argue the instruments they have chosen are reliable, however we do not know whether they are reliable as a 'suite of

instruments' or with the independent assessors they employ to undertake them (see ToR 4 response).

Critically even if it were possible to achieve high reliability and consistency, the suite of tools proposed are not valid for the purpose for which they are proposed to be used. **Validity** refers to the instruments being able to measure what they purport to quantify — in this case budgets that enable participants to meet their goals. These instruments have never been used to for the allocation of individualised budgets before and their validity is completely unknown and was not assessed in any of the research conducted thus far. **From our perspective, the NDIA has not considered this fundamental issue of validity conflating this psychometric property with reliability. An invalid instrument (or suite of instruments) can be reliable and consistent across different groups – it may just be consistently wrong.**

In the NDIA paper *IA Selection of Assessment Tools*<sup>(14)</sup>, page 19 states that "details from the assessment suite are considered collectively and with reference to the person's particular circumstances." It is therefore unclear how the assessment tools will be combined and, for example, if this is systematic, how are the tools weighted and combined? If this is done, then if someone scores highly in one domain but lowly in another it may not be evident that they need support (e.g., much higher on receptive vs expressive communication).

##### *b) Independent Pilot Evaluation*

Details of the pilot evaluation are sparse. However, based on available information it appears the evaluation was of relatively low quality and did not assess the impact and outcomes of the IAs in terms of the purpose of IAs. Firstly, there was no control group. If the NDIA wanted to make evidence-based decisions, then the most effective way to underpin an IA policy would have been to undertake a Randomised Controlled Trial where individuals opted into the process. Secondly, the numbers involved in piloting the IAs were not adequate given the diversity of participants across a range of domains (e.g., age range, impairment type, ethnic background). Only 145 surveys were done with participants and they simply assessed satisfaction with the process rather than against the aims that IAs were purported to deliver (e.g., equity, appropriate budget). Thirdly, the most important outcomes were not assessed. We do not know if the IAs led budgets that funded reasonable and necessary supports that aligned with participants goals and whether they led to better outcomes for participants in line with participants outcomes framework. We cannot know whether the IA led to better outcomes without an appropriate control group.

The NDIA claim that the validity of the process was tested through a small number of focus groups and interviews, which is not a robust approach for this purpose. Further, there was no attempt to determine whether IAs led to equitable decisions and there is no mention at all of

disadvantage in the evaluation. At best the evaluation might be able to make some determination around the feasibility of IAs, but there is no data to make any evidenced statements about outcomes. From the information presented so far on the second pilot it is not clear than any additional information is being collected on outcomes. It seems that it is still focussed on process (e.g., agree assessor understood their challenges, satisfied with length of appointment).

We also note that the evaluation was conducted by the NDIA, which is not an independent process. Instead, an independent evaluation should have been undertaken with the evaluation methods and outcomes defined **before** the evaluation was undertaken. It is best practice for the evaluation protocol to be developed and approved before the intervention is implemented and evaluated. This prevents ‘cherry picking’ the reporting of results.

**We believe it is unethical to implement such widespread change without rigorous independent evaluation of the effectiveness against outcomes agreed upon by people with disability.**

#### **ToR 6: The implications of independent assessments for access to and eligibility for the NDIS**

As outlined above, we fear that the introduction of IAs will make this a more challenging process for many on the scheme. At present those who have impairments on access lists have a relatively smooth entry to the scheme. For example, an individual who is deafblind needs confirmation by an ophthalmologist and audiologist that they have permanent and severe impairment of visual function and hearing. Under the new system, this individual will be required to undergo an IA and likely with a professional with little experience of deafblindness. Moreover, if inaccurate assessments are made of functional ability, as we believe there is great potential for as outlined above, then fewer people will receive funding through the scheme and/or receive smaller plans. Further, **the changes do not reduce the need for individually funded reports completely** as individuals will still have to prove they are eligible for the scheme in order to be assessed.

#### **ToR 7: The implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports**

As the proposed system divorces functional assessments from planning processes where goals are established, this means that decisions about what is reasonable and necessary are not linked to funding. If we do not have any sense of what an individual’s goals are then it is not possible to determine what supports

an individual’s needs. Two individuals with the same level of function may have very different determinations of what is reasonable and necessary for what they aim to achieve.

#### **ToR 8: The circumstances in which a person may not be required to complete an independent assessment**

Our view is that as IAs are currently constituted they are not fit for purpose for any individuals. However, there is good reason to assume that many aspects of the IA process will be highly traumatic for some individuals. For example, individuals with a history of sexual abuse or trauma may find some of the questions very confronting. As we know from the Royal Commission into the Abuse and Neglect of People with Disability, this is a significant proportion of people with disability. In addition, many people with disability have had negative experiences of the health systems and so having assessments undertaken by someone not known to them may be traumatising. It is also likely that some people with disability may be too anxious to be assessed (e.g., someone with autism with difficulties with sensory processing and anxiety). We need significantly more evidence to demonstrate that IAs do no harm before we see these rolled out more broadly.

#### **ToR 9: Opportunities to review or challenge the outcomes of independent assessments**

As we outlined above, one of the ways that the proposed system differs from the Tune review is in respect to the discretion afforded around the results of functional analyses and the development of a plan that is in line with the NDIS Act. What this in effect notes is that a functional analysis may not always be a good indicator of the level of supports that an individual requires to realise their human rights. The NDIS Act is quite clear about the need to support individuals to the “full extent of their capacity” and as the Tune Review notes, this may mean that there is a need for discretion with respect to the outcome of a functional assessment. The proposed system does not allow for challenge of IAs and given that this will be used to determine funding then this is highly problematic and will likely leave individuals with smaller packages that do not allow them appropriate support to achieve their goals to the full extent of their capacity.

#### **ToR 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**

We do not believe the suite of tools are suitable for any population groups. However, it is likely they are less suitable for particular groups such as First Nations

Australians and different ethnic groups. It is critical that the tools are known to be valid across all the participant groups. There is scant information of the validity of the tools across the groups. For example, even if tools are translated into languages other than English it is not clear that the nuanced meaning of questions will be retained.

### **ToR 11: The appropriateness of independent assessments for people with particular disability**

IAs may be less suitable for particular groups especially for people with fluctuating disability (e.g., multiple sclerosis, some psychological conditions) because needs will vary at different times. Participants may end up being short of funds at a time they need them most. Conducting functional assessments can be challenging even when a person knows the professional. Professor Kavanagh reports this in relation to her own son, where despite numerous attempts, his OT was unable to complete a functional assessment because he was not willing to cooperate with the process and requests to do so made him extremely anxious.

**In sum, we believe Independent Assessments should not be implemented because they have not been developed for the purposes for which they are being used, will not be aligned with the goals and needs of individual participants, will not achieve equity, will cause significant distress among participants, and may result in shifting costs to other systems (e.g., health, welfare).**

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