

Submission to the Inquiry into NDIS Independent Assessments

Centre for Disability Research and Policy

25th March 2020

Centre for Disability Research and Policy
Sydney School of Health Sciences, University of Sydney

Authors

Associate Professor Jennifer Smith-Merry, Director, Centre for Disability Research and Policy,
University of Sydney

Dr Damian Mellifont, Lived experience focused honorary Affiliate, Centre for Disability
Research and Policy, The University of Sydney

Professor Sue McAllister, Centre for Disability Research and Policy, the University of Sydney

Thank you for the opportunity to respond to the Joint Standing Committee Inquiry into Independent Assessments in the operation of the NDIS.

We wish to make several overarching comments related to the proposed Independent Assessments process. These relate to the:

- 1) Premise underpinning the independent assessment process,
- 2) Operationalisation of the process, specifically the need:
 - a. to ensure independence of the assessments from the provision of services through scheme funding
 - b. for evaluation and review of the process as it is rolled out
 - c. to shape processes carefully so that they meet the needs of specific groups
 - d. for effective and clear communication with the sector
 - e. for transparency of decision-making processes and review mechanisms, including auditing of independent assessments.

General comments on the independence of Independent Assessments.

A major concern that we would like the Standing Committee to consider is the awarding of Independent Assessor contracts to subsidiaries of organisations that also provide NDIS supports¹. The NDIA supports awarding contracts to subsidiaries². The ABC reported on 25th March, 2021³ that despite there being conflict of interest rules built into the independent assessments process large NDIS service provider companies such as Zenitas, which is headed by former NDIA CEO Rob De Luca, have been awarded contracts to provide independent assessments through subsidiaries. Subsidiaries should not be able to hold contracts for independent assessments as there is still a strong connection with the parent company. To say otherwise is to ignore the clear motivation for these companies to create the subsidiaries in the first place. The report also spoke about the lack of independence between LACs and those that had been contracted to provide independent assessments, providing the example of Advanced Personnel Management in Western Australia.

This issue needs to be addressed urgently. An independence of the assessors from the providers could be a potential benefit of the independent assessment process, but it is clear from these reports that this is not currently the case. A failure for the NDIA to uphold the independence of the 'independent' assessments will undermine the trust of people with disability in the process and the public's trust in the NDIS as a public scheme. It is clear from public discourse (see further comments below) that the NDIS constituents and public are not currently on board with the system. Public trust will be enhanced through removing the ability for subsidiaries of companies providing services from being awarded the tenders to provide independent assessments.

Specific comments:

We group our specific responses under your different areas of interest. We have not answered each point – only where we have a contribution to make.

a. the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS;

¹ Every Australian Counts (11 Mar 2021). Disability sector statement on the Australian Government's planned reforms to the National Disability Insurance Scheme (NDIS). <https://everyaustraliancounts.com.au/ndis-sector-statement/>

² ABC News Online (25 Mar 2021). As the NDIS moves to independent assessments, these companies stand to profit from the change. <https://www.abc.net.au/news/2021-03-25/david-bowen-raises-concerns-on-ndis-independent-assessments/13271354>

³ ABC News Online, 2021

Independent assessments could be positive in some circumstances. For example, in circumstances where people are 1) unable to access or facilitate their own assessments or be supported by others to do so and 2) have a limited history with service providers who may find it difficult to obtain information about their disability. For these people independent assessment processes may put them on an even footing with people who are able to obtain their own assessments with services that they have had strong and ongoing relationships with. However, we do not believe that this justifies the whole system changing. Instead, we should be bringing in better access to assessments for people who need them, and that process should be taking place with someone who has a very strong understanding of the different types of disability and complexity which have caused disconnect from services in the first place.

The NDIA justifies independent assessments as being part of the original design of the NDIS from the Productivity Commission which "... recommended that those assessing functional capacity be drawn from an approved pool of allied health professionals who are independent of the person being assessed, to reduce the potential for "sympathy bias"".4 This is a major point of justification by the NDIA, but it is based on scant evidence of this type of sympathy bias being a considerable problem. We would argue the inverse – that allied health and other health and disability professionals are professionals, who are part of regulated professions and should be trusted to do their work in a professional way. These professions are regulated under existing state and federal frameworks have their own internal processes to manage breaches of professionalism. An audit system would be more appropriate than putting in a whole other system such as independent assessments, which potentially come with their own problems, as we discuss elsewhere in this submission.

It is clear that the disability sector, including people with disability themselves are not on board with the process and this is a significant problem in the rolling out of the Independent Assessments5. The sector is not convinced because the NDIA have not done a good job of convincing them of the need, the acceptability of the process to people with disability in the trial sites and the soundness of the process. It has been suggested that consultation on mandatory assessments has been hurried and concerns as raised by individuals with disability, their families and supporting organisations have yet to be addressed6.

b. the impact of similar policies in other jurisdictions and in the provision of other government services;

It is important to consider the historical, perverse and very negative impact of eligibility assessments through the history of services for people with disabilities e.g. historical use of IQ assessments to allow/deny a child's access to educational opportunities. This was endemic in the public provided services in the past and frequently used for gate keeping to access scarce resources (never explicitly acknowledged) rather than trying to genuinely determine a person's needs. This is one of the injustices that NDIS was aiming to address. This is also an example of using an assessment for a purpose that it isn't designed for and good at doing e.g. most IQ tests are only good at discriminating performances between -2 and + 2 standard deviations, people with intellectual disability are classified as falling below -2 standard deviations, plus error margins exist that weren't taken into account, and scores on an IQ test are affected by experience and can change. Other types of assessment that have been used in this way e.g. Clinical Evaluation of Language Functioning to determine whether a child does/does not have a language disorder and should/should not access speech pathology services - the CELF is not sufficient for this and misses kids who could really benefit from

4 NDIA (2020) Independent Assessments Framework <https://www.ndis.gov.au/media/2640/download>

5 Every Australian Counts, 2021.

6 Every Australian Counts, 2021.

support. Without a strong evaluation, auditing and feedback process, in which the NDIA genuinely listens to and adapts the scheme in relation to the implementation experiences and concerns of the sector (rather than just rejects criticism) then these problems may occur in relation to the NDIS.

c. the human and financial resources needed to effectively implement independent assessments;

Accessible information should be offered to all people who have to undergo an independent assessment of their disability-related needs. This should be provided as much as possible by people with lived experience of disability.

Independent assessment can understandably be a very frightening or intimidating process for people with disability because so much is at stake in the assessment (their access to the scheme)⁷. For some people this may be even more intimidating for example if they have invisible disability and may feel that this is yet another circumstance in which they need to 'prove' their disability to others. People with invisible disability already receive lower access to disability accommodations and supports, for example in education⁸.

Psychosocial disability, or mental illness, is often fluctuating, so people will have periods of relative wellness and periods where they are very 'disabled' by the symptoms of their condition. People with psychosocial disability who are relatively well at the time of the assessment may also worry that they are not 'disabled' enough on the day of the assessment to be eligible. This may also be the case for other people with disability that is not psychosocial in origin. It is essential that people who do not feel that the assessment was able to capture their disability are able to challenge the assessment and have it repeated.

People may be worried that their disability is being assessed by people who they don't know when they have established and trusting relationships with existing clinicians. This may mean that they have to disclose their disability, which may sometimes make them uncomfortable particularly if they have been in situations where they have been ridiculed for their disability in the past, or not believed.

Some people who are very socially marginalised may not readily have anyone to support them with the independent assessment process, so this needs to be available to them.

For these reasons the following information is essential when carrying out independent assessments:

- 1) There should be clear information on the process provided by people with disability about how the process has been for them and what they should expect.
- 2) They should have access to peer support and psychological support at the time of the assessment so that they can debrief about the process if needed.
- 3) There should be independent peer workers available to be with someone if they feel that they need support during the process.
- 4) Information should be culturally accessible for Aboriginal and Torres Strait Islander people with disability. It should also be accessible for people who do not speak English as their first language or who use alternative communication.
- 5) Carers and support people should be invited to support people in the process as standard.

⁷ Every Australian Counts, 2021.

⁸ Venville, A., Fossey, E., Chaffey, L., Ennals, P., Douglas, J., & Bigby, C. (2014). Student perspectives on disclosure of mental illness in post-compulsory education: Displacing doxa. *Disability & Society*, 29(5): 792-806.

Individuals should also be aware of what information about them is being shared by and with other services and have the ability to specifically consent to their information being discussed.

d. the independence, qualifications, training, expertise and quality assurance of assessors;

No one is independent, it is not uncommon for assessors to ‘finesse’ how they use a tool to better represent progress (not misrepresent it though – ethical practice should cover that!), all assessment is subjective and prone to error and bias (even when it involves a ruler) that needs to be managed by triangulating a range of observations and should involve the person with a disability to ensure their needs and aspirations have been accurately captured. Validity resides in whether the results of an assessment can be validly used to make a judgement and guide action. Tools are not in themselves valid, training the user of the tool rarely changes the quality of their ratings (bad ones stay bad). It is important then that assessors are audited and receive training in a very broad range of disability and life circumstances. Pilots to date indicate that assessments are being conducted by health professionals who are lacking in experience and knowledge about disability⁹. The Australian Autism Alliance (2020) argues that autism awareness training should be mandatory for all assessors as a minimum, but the same also goes for other types of disability¹⁰.

The need for assessors to undertake the assessments might affect the availability of professional therapists to assist NDIS participants (especially in regional and remote locations)¹¹.

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

The new tool, if not implemented effectively has the potential to be ableist. The new tool has been described as “‘dehumanising’ and a ‘nightmare’” - some pilot respondents claim that a requirement to focus on the things they cannot do is traumatising¹². An architect of the Scheme, Professor Bruce Bonyhady, argues that instead of addressing the client’s goals and aspirations, the new tool focuses on impairments and acts to compartmentalise people¹³.

f. the implications of independent assessments for access to and eligibility for the NDIS;

As discussed elsewhere in this submission, there may be particular problems with assessing disability in a limited timeframe in people with fluctuating needs, such as people with psychosocial disability¹⁴. These people are already underrepresented in the scheme and this

⁹ Dickinson, H. (14 Mar 2021). ‘Dehumanising’ and ‘a nightmare’: why disability groups want NDIS independent assessments scrapped. <https://www.themandarin.com.au/151464-dehumanising-and-a-nightmare-why-disability-groups-want-ndis-independent-assessments-scrapped/>

¹⁰ Australian Autism Alliance. (14 Oct 2020). Statement on the proposed introduction of mandatory NDIA determined assessments in the NDIS. <https://australianautismalliance.org.au/home/independentassessments/>

¹¹ Every Australian Counts, 2021.

¹² Dickinson, 2021.

¹³ McGrath, P., & McClymont, A. (2021). NDIS architect Bruce Bonyhady urges rethink of independent assessments. <https://www.abc.net.au/news/2021-03-18/ndis-architect-bruce-bonyhady-slams-independent-assessments/13256160>

¹⁴ McGrath and McClymont, 2021.

under-access may be further entrenched if independent assessments are not carried out with a specific approach that is cognisant of the needs of people with fluctuating disability needs¹⁵.

g. the implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports;

See comments above about the need for independence of 'Independent Assessments' from organisations which also have disability providers within their organisation broadly understood.

h. the circumstances in which a person may not be required to complete an independent assessment;

Independent assessments are not necessary for most people coming into the scheme. They should only be used where people are not able to access their own clinical support teams for assessments, for example in the case of people who may have been for a long period without the provision of any services (e.g. homeless people, or those that have otherwise been severely underserved in the past).

i. opportunities to review or challenge the outcomes of independent assessments;

This needs to take place on both an individual level for people who have had their own assessments and are unhappy with the process and at a scheme level. It should happen through the following mechanisms:

1. A process of following up each assessment to determine the acceptability of the assessment process to the person with disability and, where relevant, their family-carers. There should be mechanisms for providing this information anonymously.
 2. Undertake an open and independent evaluation of the services offered by independent assessors. This should be commissioned by the government (rather than the NDIA, who has a vested interest in the outcome) and publicly released so that the results can be scrutinised.
 3. There should be data on the assessment processes collected and made publicly available on a quarterly basis. This should be compared to practices prior to the independent assessment process being implemented.
- 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;

Concerns have been raised that the tool is not safe for minorities including: First Nations persons; persons from linguistically or culturally diverse backgrounds; and LGBTIQ persons¹⁶. The evaluation of the scheme should report data for each of these groups, and collect anonymous feedback from participants in each cohort.

k. the appropriateness of independent assessments for people with particular disability types, including psychosocial disability;

¹⁵ Smith-Merry, J. et al (2018) *Mind the Gap: The National Disability Insurance Scheme and Psychosocial Disability* <https://www.sydney.edu.au/health-sciences/documents/mind-the-gap.pdf>

¹⁶ Dickinson, 2021

People with communication disabilities arising from intellectual disability, cerebral palsy, brain injury, mental illness etc – an independent assessor may not be able to adequately communicate with them to determine their responses and aspirations.

Psychosocial disability, or mental illness, is often fluctuating, so people will have periods of relative wellness and periods where they are very ‘disabled’ by the symptoms of their condition. People with psychosocial disability who are relatively well at the time of the assessment may also worry that they are not ‘disabled’ enough on the day of the assessment to be eligible. This may also be the case for other people with disability that is not psychosocial in origin.

Concerns are also held for some applicants with specific types of neurodivergence. Some autistic persons might find the assessment process to be anxiety producing which could present a barrier to their participation¹⁷. For instance, in focusing on deficits, the assessment of an autistic pilot participant reportedly “didn’t go to plan” and needed to be terminated early¹⁸.

About the Centre for Disability Research and Policy

The Centre for Disability Research and Policy (CDRP) at the Faculty of Health Sciences of the University of Sydney aims to change the disadvantage that occurs for people with disabilities. We do this through addressing their social and economic participation in society, and their health and wellbeing. By focusing on data that demonstrates disadvantage, we can develop models of policy and practice to better enable support and opportunity for people with disabilities.

About the authors

Associate Professor Jennifer Smith-Merry is Director of the Centre for Disability Research and Policy (CDRP) in the Faculty of Medicine and Health at the University of Sydney. Her academic research has focused on policy and service development, primarily in mental health and the study of adverse events. Jen is lead Chief Investigator on multiple grants which aim to evaluate or develop policy and services in disability and mental health. She works closely with people with a lived experience of disability and has a strong interest in the value of lived experience in informing policy and service design. Jen led the development of the *Mind the Gap* report into the National Disability Insurance Scheme (NDIS) and psychosocial disability.

Dr Damian Mellifont is a lived experience researcher with the Centre for Disability Research and Policy at The University of Sydney. Damian's work informs evidence-based ways to redress ableism and to help to improve the social and economic inclusion of people with disability.

Professor Sue McAllister has over 35 years experience as a speech pathologist, clinical educator, project manager, and academic. Her research and education work is concerned with ensuring that the community can address its health and wellbeing goals through accessing a high quality disability and health workforce.

¹⁷ Australian Autism Alliance, 2020

¹⁸ Moore, A. (6 Jan 2021). NDIS autism assessment pilot leaves young man ‘embarrassed’. Retrieved from <https://www.abc.net.au/radio/melbourne/programs/breakfast/nicole-rogeron-ndis-assessment/13036182>