



Joint Standing Committee into the NDIS

Inquiry into Independent Assessments

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Contents

Contents.....	2
Endorsements	3
Who is the Physical Disability Council of NSW?.....	4
Recommendations	5
Introduction	6
Response to the Terms of Reference	8
Conclusion	21
References.....	22

Endorsements

This submission is endorsed by:



Who is the Physical Disability Council of NSW?

The Physical Disability Council of NSW (PDCN) is the peak body representing people with physical disabilities across New South Wales. This includes people with a range of physical disability issues, from young children and their representatives to aged people, who are from a wide range of socio-economic circumstances and live in metropolitan, rural and regional areas of NSW.

Our core function is to influence and advocate for the achievement of systemic change to ensure the rights of all people with a physical disability are improved and upheld.

The objectives of PDCN are:

- To educate, inform and assist people with physical disabilities in NSW about the range of services, structure and programs available that enable their full participation, equality of opportunity and equality of citizenship.
- To develop the capacity of people with physical disability in NSW to identify their own goals, and the confidence to develop a pathway to achieving their goals (i.e. self-advocate).
- To educate and inform stakeholders (i.e.: about the needs of people with a physical disability) so that they are able to achieve and maintain full participation, equality of opportunity and equality of citizenship.

Recommendations

Recommendation 1

That the NDIA postpones the implementation of independent assessments to allow for:

- *an assessment into the feasibility of the proposed tools in the context of choice and control for participants under the NDIS scheme,*
- *the development of the Quality Assurance Framework,*
- *a more thorough assessment of the structure of the proposed independent assessment process, and*
- *the opportunity for additional input and consultation across the disability community.*

Recommendation 2

As part the preparation for an independent assessment, require assessors to have pre-assessment contact with the participant to establish rapport, address any concerns that the participant might have and to ensure that the participant has all the information they need.

Recommendation 3

That the new legislation stipulates that assessments will not be mandatory, that for people entering the scheme, they will only be used as necessary (e.g. when all other evidence provided is not sufficient) and, in the case of people already on the scheme, they will only be used as the need arises (e.g. in instances where it is likely that someone's support needs have changed dramatically).

Recommendation 4

That people with stable, permanent conditions where it is expected that there is no change in functional capacity be excluded from the requirement to undergo an independent assessment until such time as their circumstances change.

Recommendation 5

That the NDIS should have the discretionary power to exempt an individual from having to utilise an independent assessment as a mechanism for assessing functional capacity, should there be compelling reasons to do so, based on the individual's specific circumstances.

Recommendation 6

That the NDIS establish a framework which allows participants to lodge complaints about the Independent Assessment process and seek appropriate remedies.

Introduction

As the peak representative body for people with physical disability across NSW, PDCN welcomes the opportunity to provide feedback to the Joint Standing Committee on the NDIS and its inquiry into Independent Assessments (IAs).

In June 2019, the Federal Government commissioned a review of the National Disability Insurance Scheme (NDIS) Act 2013, to be undertaken by independent expert Mr David Tune AO PSM, otherwise known as the Tune Review. The aim of the review was to improve the overall experience for NDIS participants; by cutting legislative 'red tape' and streamlining the process.¹ We understand that Independent Assessments (IAs), are seen as a way of improving the overall functionality of the NDIS including overall participant outcomes.

We agree that there are current problems in terms of the wide variation of practical outcomes for participants, and that those variations can be driven by disadvantage.

Assessing functional capacity could provide a more accurate assessment of a person's support needs, enhance efficiency across the assessment process and provide for a more equitable distribution of supports and services across the scheme, but we are highly uncomfortable with the suggestion that independent assessments would be the primary tool for determining, first, a person's eligibility for the NDIS, and secondly, the supports and services they receive. We are also concerned about the proposed model of conducting IAs, which we will discuss across this submission.

We understand that IAs will be rolled out across applicants to the NDIS scheme in mid-2021 and that it is expected that all NDIS participants will be required to do IAs by the end of the year.

We note that several allied health organisations have already successfully bid for tenders to conduct IAs – we are gravely concerned that this process has been finalised before the conclusion of this Inquiry.

It appears that IAs will occur regardless of the views of participants and their advocates, and this undermines the reputation of the scheme across the disability community. This was raised as a potential concern within the Tune Review, where it was specifically recommended that the NDIA should not implement a closed or deliberately limited panel of providers to undertake functional capacity assessments and that engagement issues be monitored to prevent loss of confidence or disengagement.²

As part of our research for this submission, PDCN, together with Muscular Dystrophy NSW (MDNSW) and Spinal Cord Injuries Australia (SCIA), conducted a roundtable discussion across our respective memberships to discuss the changes. As stated above, some of the participants of the roundtable had participated in the pilot programs themselves and were able to talk to their experiences.

A common theme from the roundtable was concern and scepticism as to whether Independent Assessments as the mechanism for determining functional capacity will actually improve participants access to the funding and supports that they need, with several participants interpreting the changes as a loss of choice and control. Some said that they would actively challenge being 'forced' to use IAs.

Despite recorded participant satisfaction across the pilot program, we know that, for a significant proportion of those who are already in the scheme, there is a sense that IAs represent a step

¹ Tune, D., 2019, *Review of the National Disability Insurance Scheme Act 2013*, p 67 at 4:37

² Tune review, p 67 at 4:37

backwards in terms of realising their goals, rather than forwards. We have received contradictory information to the high rates of participant satisfaction cited by the NDIA, from people who have participated in the pilot.

These people spoke to a range of issues with the proposed structure, including extensive amounts of questions within a short time frame, as well as rigidity and the possibility of misinterpretation around questions, the conduct of assessors, and little concern as to the functional limitations of participants to fully participate in these IAs under the proposed structure, which are all concerning to us.

There is likewise no assurance in terms of fast turn arounds on reviews of decisions based on Independent Assessments, and we would want to see the capacity to effect reviews of decisions based on IAs.

There is suspicion that the primary motivation for the change is cost cutting across the NDIS, and that positive client outcomes are secondary to such cost cuts. There is also concern that independent assessments will be utilised as a tool to try to funnel people out of the scheme or to reduce the supports and funding they currently receive.

"I was asked what supports I might need to get out of the NDIS [in the independent assessment meeting], I have a permanent disability, I can't exit the scheme"

We consider that any scepticism is valid and that people with physical disability have good cause to be concerned with IAs as they have been envisioned to date. The Tune review supports functional capacity assessments as a supplementary information gathering tool - 'it is worth implementing nationally for every person with disability who would like to test their access for the NDIS or who require further evidence to support decision makers about the supports in their plan' – but not as the primary or sole tool for determining a participant's supports or funding.³

PDCN considers that IAs may be a useful tool in achieving this, but not to the extent that other important assessment tools are overlooked or excluded. People with disability deserve the right to exercise choice and control in terms of how they communicate their functional needs to the NDIS, and to that end, we consider that the Tune review's recommendations that IAs be one of a range of tools that can be chosen by a participant is both sensible and considered.

We also highlight that perceptions regarding IAs will vary considerably depending on whether someone is attempting to access the scheme for the first time or whether they are already participants - for those who are already in the scheme, there is a sense that IAs represent a step backwards in terms of realising their goals, rather than forwards.

We understand that the NDIS – and NDIA – are still in their infancy. We want the NDIS to work. We want it to be as effective and efficient as possible. We want people with disability to have choice and control in accessing the services and supports they need. We also understand the rationale behind the introduction of IAs, however we do have several concerns and we will raise these in our submission.

Our response will not address all areas of the terms of reference, rather the ones that we believe we are most able to provide useful comment on, as they relate to the experiences of our membership. We feel it is premature to respond to other areas raised in the terms of reference until the Access and Eligibility Policy has been finalised, Independent Assessments are part of legislation, and have been part of the process for some time.

³ Tune Review, p. 65 at 4:29

Response to the Terms of Reference

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

Reasoning and justification for IAs

The NDIA advises that it seeks to apply independent assessments to ensure there is fairness, equity and consistency in decision making.⁴

The Independent Assessments Framework outlines the rationale behind the need for independent assessments, primarily being that there is too many inconsistencies and variabilities in the experience of people providing information, the assessment tool used, the design of the assessment tool, the level of detail in reports and assessments, how recent the assessment was done, method of assessment, interpretation of results and standardisation of assessments.⁵

The NDIA has spoken to a range of barriers which those seeking to access the scheme, including costs. In its public messaging the NDIA states:

We want all people, regardless of their situation to have the same access to internationally recognised, evidence based assessments.

In June 2019, the Federal Government commissioned a review of the National Disability Insurance Scheme (NDIS) Act 2013, to be undertaken by independent expert Mr David Tune AO PSM, otherwise known as the Tune Review. The aim of the review was to improve the overall experience for NDIS participants; by cutting legislative 'red tape' and streamlining the process.⁶

Mr Tune presented his report to the Government in January 2020. It made 29 recommendations to improve the participant experience. In Chapter 4 – Evidence to Support Decision-Making, it discussed functional capacity assessments as a mechanism for removing the burden of proof for participants and in gaining an accurate picture of the supports and services needed by the participant. Its key findings included:

- *Standardised functional capacity assessments would improve the quality and consistency of NDIA decisions. If undertaken at the point of access it would also improve the participant experience by mitigating the need for the participant to provide further information about their functional capacity later in their NDIS journey.*
- *The administrative and financial burden felt by both prospective participants and participants to provide evidence to the NDIA should be minimised.*
- *Greater clarity should be provided surrounding the requirement for, use and form of information required to support decision-making.*
- *The impact of secondary impairments should not be a barrier to planning. A participant's 'primary' disability does not solely determine the supports funded or not under the NDIS.⁷*

The Tune Review goes on to make the following recommendation in support of the use of IAs in some circumstances:

The NDIS Act is amended to:

⁴ NDIS 2020, *Consultation paper: Access and Eligibility Policy with independent assessments*, <https://www.ndis.gov.au/community/have-your-say/access-and-eligibility-policy-independent-assessments>, accessed 17/12/20

⁵ NDIS 2020, *Independent Assessment Framework*, <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-framework>, accessed 14/1/21

⁶ Tune Review, at p. 17

⁷ Tune Review, at p. 59

Provide discretionary powers for the NDIA to require a prospective participant or participant undergo an assessment for the purposes of decision-making under the NDIS Act, using NDIA-approved providers and in a form set by the NDIA.

The legislation should be amended to recognise the importance of appropriate assessments and what they can be used for, noting it is a reasonable expectation that participants might need to undertake further assessments from time to time to ensure their plans remain fit for purpose.⁸

It is important to note that the Tune review in envisioning these discretionary powers also stated:

*'it [IAs] is worth implementing nationally for every person with disability **who would like to test their access for the NDIS or who require further evidence** to support decision makers about the supports in their plan'⁹*

The report does not advocate for the exclusive use of IAs.

Our response

We agree that a focus on functional capacity is a useful tool to determine the type of supports and services an individual needs, and that there is value in moving away from a diagnosis-based assessment which may not account for the specific needs of an individual.

We know the way that disability manifests across individuals with the same diagnosis is different and it is vitally important to recognise this.

At the same time, we think that the NDIA oversells the value of IAs, particularly as the sole mechanism, either for assessing an individual's suitability to access the Scheme or to determine a participant's supports and services. We would not support a model based exclusively on IAs.

In terms of addressing inequities resulting in supports and funding, we agree that free assessments are a major benefit for people who otherwise have to pay for specialist reports, should they not already have them, or where they would struggle to afford them.

We anticipate inconsistencies across assessments will still occur and that pockets of disadvantage will continue to be identified.

We anticipate that there will still be variations across the capabilities of independent assessors to accurately identify a participant's functional capacities, which may prove problematic in instances where there are limited numbers of assessors, for example, rural and regional areas, or where some Independent Assessors are highly specialised or have particular skills, e.g. speak a community language. We also see potential difficulties in conducting independent assessments in remote and regional areas where it may not be possible to source independent health professionals that are not otherwise connected to the NDIS.

We may see similar pockets of disadvantage develop, not to mention backlogs and delays in assessments in areas where assessors are in limited supply – a situation that is currently avoided by using the participant's preestablished network of health professionals. The NDIA envisions a range of different modes that the IAs can be conducted in, including phone or via video link, which was perhaps in part offered to overcome barriers such as distance from an Independent Assessor – but

⁸ Tune Review p. 61 at 4.11

⁹ Tune review, p 65 at 4:29

we are concerned about the quality of such forms of assessment– many of our members have stressed that they feel that it is important to be assessed face to face.

We anticipate that there will be greater levels of appeals

Likewise, we cannot envision that there will be less appeals as a result of this process. If anything, placing participants in a scenario where they may not trust the Independent Assessor to be able to understand their level of functional capacity may well make participants pre-disposed to find fault across the decisions. The Independent Assessments could be interpreted as removing the choice and control over the information that participants choose to provide for the purposes of assessment and replacing this with a mechanism that they do not understand.

We are concerned that the IA models used may not be expansive enough to capture the full scope of what an individual's needs may be. In this sense, it may not be so much a case of what is covered under the questions, so much as what is not included - and this may speak to underlying biases and perceptions about disability generally. For example, there has recently been significant controversy over a Federal Court ruling in favour of a woman living with multiple sclerosis who wanted to fund sex work services in her plan. The NDIS had initially refused the funding before the woman won an appeal to the Administrative Appeals Tribunal (AAT) which reversed the refusal of funding made by the NDIS.¹⁰

IAs, used exclusively, and without the scope to expand on an individual's specific needs, may be used as a tool to limit the areas in which an individual can seek supports and services. We believe that this Parliamentary Inquiry should look at IAs in light of the broader political issues around decision making power particularly as they relate to specific supports and services. We do not want to see a situation, like the case referred to above, where undue influence is exerted by any particular Government to determine what is "*reasonable and necessary*".

It is outside the scope of our submission to substantially analyse the scope of questions that have been asked in the Pilot. We understand that international tools will be used to determine functional capacity, including tools used by the World Health Organisation.

We are concerned that the tools may not be fit for purpose – specifically that they may not fit well within a framework that is directed by the goals of a participant. We need assurance that the tools will assess functional capacity over all foreseeable goal setting situations and if not, that the assessment process has sufficient flexibility to assess the functional capacities of individuals in "novel" circumstances.

Likewise, we are sceptical of the reported levels of satisfaction with IAs under the pilot program. We note that there were only 35 responses reported out of 510 pilot participants. We would argue that this is not statistically significant enough to support the government's claim that 91 per cent of participants or their representatives in the first trial reported "high levels of satisfaction with their appointment".¹¹

We have seen no basis for claims of patient bias

¹⁰ Hermant and Clark, 2019, "Woman with disability wins NDIS funding for sex therapist in 'precedent-setting' case", ABC News, <https://www.abc.net.au/news/2019-07-11/ndis-to-pay-for-sex-therapist-after-landmark-ruling/11298838>, accessed 24/3/21

¹¹ Clun, Rachel, Sydney Morning Herald, 91 per cent of participants or their representatives in the first trial reported "high levels of satisfaction with their appointment", December 23, 2020 < <https://www.smh.com.au/politics/federal/just-not-ok-only-6-per-cent-of-ndis-trial-participants-completed-survey-20201221-p56pbc.html> > accessed 26 March 2021.

Lastly, we feel that it is necessary to address the premises that Independent Assessments will ensure that health professionals do not overstate the support needs of their patients because of subconscious or deliberate 'patient bias'. We understand that this was raised as a concern by the Productivity Commission. We are dubious as to whether patient bias skews NDIS assessments and would want to see evidence in support of this claim.

Notwithstanding this, we point out that a process which switches the focus to the individual (and to a limited extent a support person with an understanding of their functional capabilities) would, to our minds run an even greater risk that the individual would have less objective understanding of their capacities and limitations, than their health professionals.

The development of IAs

Full rollout of IAs across both people attempting to access the scheme and current participants is earmarked for the end of the year.

We note that the NDIS has only been fully operational nationally since last year. We are concerned that the NDIA is rushing the implementation of IAs and has provided limited scope for consultation with people with disability, notwithstanding the Minister's comments in August 2020 that he would "... ensure people with disability have a seat at the table when it comes to implementing these reforms."¹² We have seen little evidence that people with disability have been consulted on the process, and in fact, the tight timeframe - with IAs to be introduced for prospective participants in early 2021, and for those already on the scheme from mid-2021¹³ - it is hard to believe that sufficient consultation has been undertaken. We note that Independent Assessment pilots have been being undertaken since 2018.

The Tune review specifically highlights that building the trust of participants, their families and their carers when engaging with NDIS processes should be key within the next stage of NDIS implementation to ensure that the NDIA is able to deliver an efficient and effective scheme.¹⁴ The Tune review also stated in specific reference to IAs that:

This change in approach [the use of IAs] will require extensive consultation with participants, the disability sector, service providers and the NDIA workforce.

Fundamentally, however, the success of the program will largely be dependent on:

- a. the willingness of prospective participants and participants to work with NDIA-approved functional assessors*
- b. those assessors providing truly independent functional capacity assessments, so they are not perceived as agents of the NDIA or a tool designed to cut supports from participants.¹⁵*

We consider that the NDIA is fast tracking IAs, with insufficient consultation across the sector. This is resulting in confusion and distress amongst the disability community, which is counterproductive to the reputation of IAs and the Scheme as a whole.

Modelling of the IAs

¹² Hermant and Clark, op cit.

¹³ NDIS, *Independent Assessments: Pilot learnings and ongoing evaluation plan*, <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-pilot>, accessed 26/2/21

¹⁴ Tune Review, p 35 at 2.47

¹⁵ Tune Review, p. 66 at 4:33

As stated, we are very concerned that the IA models used may not be expansive enough to capture the full scope of what an individual's needs may be. We are concerned that the importation of assessments for functional capacity, without thought as to how these assessments might apply in terms of the domestic and international rights that people with disability can expect in the Australian context may result in gaps. These gaps take choice and control away from people with disability and may be exploited to promote particular political agendas.

It needs to also be recognised that functional capacity assessments represent a significant shift in how individuals view how they live with disability. It may be that the list of questions asked to those undergoing an IA are difficult to contextualise in terms of the practical impact of that functional impairment – for instance, a question could ask “can you raise your hands over your head”, but it may not be obvious to the person being asked that a negative response to that question might highlight a need for assistance getting dressed.

What we are highlighting here is that it may be harder for participants to pick up or elaborate on contexts that are not covered by the range of questions. Participants will be able to challenge the decisions as a result of information provided by an IA, but not the content of the IA itself.

The Tune report specifically provided that clear and accessible publicly available information, including on the NDIS website, on the functional capacity assessments being used by the NDIA should be provided. While information is provided regarding the particular scales that may be employed, this information is not clear, and already we can see that some of the scales may not apply in the context for which they are intended to be used.¹⁶

The removal of the Access lists will lead to additional applications without merit.

At the same time, IAs will apply for those seeking to access the scheme without the existing Access lists. Whilst we understand the philosophy guiding the decision to remove these lists as a mechanism for pre-emptively determining how suitable someone might be for the Scheme, we consider the lists to be a useful tool for expectation setting – they allow someone to make a prima facie assessment about whether they might be eligible for the scheme, and if so, whether the process of being assessed will be fairly straightforward (in the case of List A¹⁷) or involve more in-depth assessment of the person's capabilities (List B).¹⁸ Likewise, List D sets out a list of conditions where early intervention supports will be assumed necessary.¹⁹ List C sets out a range of supports across state and territories that will be assumed to meet the requirements without further evidence.²⁰

We would be concerned that the removal of the lists might result in an increased volume of applications from individuals who do not meet requirements for the NDIS, and a greater volume of inquiries relating to both early intervention and whether supports and services would ordinarily be covered under the scheme. There is still value in retaining information that gives potential participants a quick assessment of whether there is value in applying to scheme.

¹⁶ Tune Review, p 66 at 4:34

¹⁷ NDIS, *Operational Guidelines – Access to the NDIS – List A*, <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/list-conditions-which-are-likely-meet-disability-requirements-section-24-ndis-act>, accessed 5/3/21

¹⁸ NDIS, *Operational Guidelines – Access to the NDIS – List B*, <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/list-b-permanent-conditions-which-functional-capacity-are-variable-and-further-assessment-functional-capacity-generally-required>, accessed 5/3/21

¹⁹ NDIS, *Operational Guidelines – access to the NDIS – List D*, <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/list-d-permanent-impairment-early-intervention-under-7-years-no-further-assessment-required>, accessed 5/3/21

²⁰ NDIS, *Operational Guidelines – Access to the NDIS – List C*, <https://www.ndis.gov.au/about-us/operational-guidelines/access-ndis-operational-guideline/list-c-defined-programs>, accessed 5/3/21

We do not see a need to remove List A, List B or List D where there is no real ambiguity in terms of whether someone might reach a threshold of functional impairment either to be covered under the scheme, or if they are underage, to receive early intervention as a precursor to entering the scheme. Likewise, if a defined program has met the requirements to be NDIS approved, we do not see why this information should not be available to assist people with disability make informed choices regarding the programs they seek to utilise.

If the existing lists are removed, some guidance should be available based on the functional capacity model to provide people with an indication of whether they might be eligible for the NDIS. There may be some use in looking to applying a percentage scale of an individual's functional capacity verses full functionality, like the Civil Liability Act 2002 (NSW) which applies a percentage scale for determining civil damages.

The appointment of Independent Assessors

We are concerned with how the appointment of IA providers has operated to date.

The Tune Report's recommendations on this point were as follows:

One of the biggest risks in implementing the new functional capacity assessment process will be disengagement – that is, people with disability refusing to interact with any of the NDIA-approved providers....given this, the depth of the NDIA-approved panel of assessors must be sufficient to mitigate any engagement risks for these cohorts as well as any other issues relevant in specific locations, communities, or for particular disability types.

*Therefore, this review considers that, in at least the short term, **the NDIA should not implement a closed or deliberately 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.²¹*

The Tune Review specifically recommended key protections around this, including participants having the right to choose which NDIA-approved provider in their area undertakes the functional capacity assessment.²²

Notwithstanding these recommendations, eight companies have already been appointed to carry out the IAs and we are gravely concerned by reports that several of these companies have parent companies that are, themselves, NDIS providers.²³ We have also seen evidence that at least one parent company is advertising for Independent Assessors under its company branding.²⁴

Regardless of whether there is a direct conflict of interest in these appointments, the fact that the companies appointed by the Federal Government to conduct IAs appointed have direct association with NDIS providers, is a serious reputational blow to IAs and causes us to doubt the integrity of the process.

²¹ Tune Review, p 67 at 4:35-4:37

²² Tune Review, p 66 at 4:34

²³ McGrath, Pat, and McClymont, Alison, ABC News Online, *As the NDIS moves to independent assessments, these companies stand to profit from the change*, 25 March 2021 < <https://www.abc.net.au/news/2021-03-25/david-bowen-raises-concerns-on-ndis-independent-assessments/13271354>> accessed 25 March 2021.

²⁴ Ibid.

Similarly, we do not know what the Quality and Safeguards will look like around Independent Assessors or even whether the Quality and Safeguards will be finalised in time for the proposed rollouts.

Given the important role that Independent Assessors are expected to carry out and problems that can often occur when outsourcing to a for profit service it is imperative that robust Quality and Safeguards mechanisms are employed and that participants have mechanisms to report instances where assessors do not exhibit the appropriate standards of service.

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

The introduction of the NDIS marked a significant shift in the delivery of social care in Australia. Its framing – including terms such as “choice and control” and “individualised funding packages” suggested that it would move the system of disability support away from relying on the medical model of disability towards the social model.

We would suggest that with the introduction of IAs, this is *not* the direction the NDIS is heading. The NDIA has made it clear that it is introducing IAs as a way of ensuring the long-term viability of the scheme – but we suggest this undermines the foundations of the scheme –namely, choice and control.

The social model of disability takes the view that disability is a product of the environment; that people are disabled because society is set up in a way that isn’t accessible.²⁵ There has been a fair bit of interest in the introduction of the NDIS, and research into its conceptualisation, particularly in the UK.

Needham and Dickinson²⁶ believe that the NDIS is insurance focused, rather than personalised. In fact, they suggest that rather than promoting individualisation and personalisation the NDIS is “emphasizing risk-pooling and the minimizing of future liabilities.”²⁷ We would suggest that with the introduction of IAs, this is the direction the NDIS is heading. The NDIA has made it clear that it is introducing IAs as a way of ensuring the long-term viability of the scheme – but we suggest this undermines the foundations of the scheme – and the individual’s right to choice and control.

In its 2011 report, the Productivity Commission envisioned an “insurance scheme”²⁸ for people with significant disabilities, but it also stated that the main function of the NDIS “would be to fund long-term high quality care and support (but not income replacement) for people with significant disabilities.”²⁹ In essence, the Productivity Commission envisioned a scheme that was long-term – to provide people with certainty they would continue to receive care and supports, and not be at the whim of government budget cycles.³⁰ It would take a long-term view and have a strong incentive to fund cost effective early interventions and collect data to monitor outcomes and ensure efficiency.³¹

²⁵ Goering, S., 2015, *Rethinking disability: the social model of disability and chronic disease*, Current Reviews in Musculoskeletal Medicine, vol. 8, iss. 2, p. 134–138, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4596173/>, accessed 26/2/21

²⁶ Needham, C. and Dickinson, H., 2018, ‘Any one of us could be among that number’: Comparing the Policy Narratives for Individualized Disability Funding in Australia and England, Social Policy and Administration, vol. 52, issue 3, pp. 731-749, <https://onlinelibrary.wiley.com/doi/full/10.1111/spol.12320>, accessed 26/2/21

²⁷ *ibid*, note 6

²⁸ Productivity Commission 2011, *Disability Care and Support*, Productivity Commission Inquiry Report Volume 1, <https://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume1.pdf>, accessed 19/2/21

²⁹ *ibid*, p. 2

³⁰ *ibid*

³¹ *ibid*

The concept of conducting a functional capacity assessment to determine the level of support a person requires is not new.

Several insurance schemes in Australia follow a similar process (see NSW's Icare Lifetime Care and Support, Victoria's WorkSafe, MAIC Queensland, - all these schemes use some form of "assessment" to determine eligibility to the scheme and assess ongoing need.

The difference is that these schemes are for people to recover from an injury or accident, and they are sometimes expected to make a full recovery, obviously with some exceptions.

They are also looking at a person's ability to return to work. In these circumstances, the process of an independent assessment is somewhat justified. But for all people with disability that is not a result of accident or injury, the process should be different. The difference here is that a large proportion of people on the NDIS have had their disability for life, and there are medical professionals who have been treating and working with them for many years and have a good understanding of their capacity. NDIS participants we spoke to are concerned that this will not be captured adequately by an independent assessor, and that it also adds another, unnecessary layer to the process. Additionally, it will mean that participants will have to repeatedly re-tell their story, which can be exhausting, distressing and time consuming.

Example – the Icare Scheme

If we take the NSW nominal insurer, Icare, as an example of a similar scheme, we can see that functional capacity assessments are a part of the process for assessing a participant's entry onto the scheme and determining their level of care and supports. According to the guidelines, the assessment process is based on three key themes³², which are: person-centred, best practice, and choice and control. Within 'best practice', the guidelines include five key sources of knowledge to determining care and support – evidence, narrative, general reasoning, shared view, pragmatic reasoning. PDCN would like to see these be considered as part of the guidelines for undertaking independent assessments.

A Lifetime Care participant that PDCN spoke to also highlighted that in terms of the original assessment it was done without involving them directly – because after the accident, they did not want to re-traumatise the person by asking them to relive it to a stranger.

This participant also indicated that ongoing, the process of assessing capacity can be quite informal. In this participant's case, it is treated as a "check-in" to see how the person is going and if anything has changed. It is obviously different for everyone, and for people with high needs a My Plan process is undertaken, but it is a process that is flexible. The participant PDCN spoke to indicated that not all participants have to undertake the process in a formal way, but it is a way to request changes to supports.

The point here is in the different approach taken – and for people who will never exit the NDIS, and will always require some level of support, perhaps a different approach is needed, such as the one taken by Icare, so that they don't have to explain their whole life to someone every few years.

³² Icare 2020, Planning Facilitators Manual – Lifetime Care and Workers Care 3rd edition, <https://www.icare.nsw.gov.au/practitioners-and-providers/healthcare-and-service-providers/planning-with-an-injured-person#gref>, accessed 12/3/21

Functional capacity assessments are also used throughout the world to assess a person's ability to work (or return to work)³³, but again these are mostly framed around an eventual exit from the scheme.

PDCN recognises that for some people it may be possible for them to exit the NDIS, with the right supports and in an appropriate time frame, however for the majority of our members, being people with physical disability, they will always require care and support and may never be in a position to exit the scheme.

In addition, these insurance schemes are used for motor accidents or workplace accidents and the functional assessments used focus on three types of physical disability – spinal cord injuries, acquired or traumatic brain injuries, and burns. The NDIS is for people with all types of disability, not just physical ones, and any “tools” used must take this into account.

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

“[the assessor] just literally read out the questions. They said, that’s all I’m here to do, just gather data.”

“I was asked [by the assessor] what supports I might need to get out of the NDIS [in the independent assessment meeting], I have a permanent disability, I can’t exit the scheme”.

- Comment by pilot participants, 11 February 2021

We have heard some worrying information regarding the quality of assessors over the trial. The above quotes are drawn from information from pilot participants – those participants reported being generally unhappy with the independent assessment and lacking confidence that their needs would be met. Assessors should be allied health professionals with expertise specific to the participant's disability or disabilities. They should be able to demonstrate that they meet the relevant accreditation standards for their profession.

In the case where the individual presents with multiple disabilities which affect different aspects of their functional capabilities, multiple suitably trained assessors should be utilised. We have heard conflicting information as to whether a single Independent assessor will be appointed who is qualified in treating the participant's primary disability or whether multiple assessors will be utilised, and if so, what such a model might look like.

We can anticipate that there will be many participants that will present with multiple, often entirely unrelated functional capacity issues – for example, in the case of someone who has experienced stroke which may result in reduced functioning across both their cognitive and physical capabilities.

In such a context, we would strongly push for both an independent assessor specialising in physical capacity and an assessor to assess cognitive function as the fairest way to gain an accurate picture of the participant's overall capabilities and limitations.

Assessors should be sufficiently trained and knowledgeable enough to understand the potential types of challenges an individual might experience across their day-to-day life but also realise that every person's experience is unique - to be able to know the questions to ask, but not assume that they know the answers.

³³ Chen, J.J, 2007, *Functional Capacity Evaluation and Disability*, The Iowa Orthopedic Journal, vol. 27, pp. 121-127, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2150654/>, accessed 26/2/21

They should have demonstrated skills in assessing patients, be familiar with the suite of assessment tools and know how to apply them appropriately.

Given the large volume of questions that assessors will have to ask across a limited timeframe, they must be able to quickly establish trust and rapport with the participant. Rather than attempt this during the assessment itself, we would recommend that independent assessors arrange a short pre-assessment contact with the participant to introduce themselves, ensure that the participant is sufficiently prepared and to answer any concerns the participant may have.

We consider that such a process may greatly enhance the participant experience, and many provide an opportunity for the participant to pre-emptively raise any concerns about the choice of assessor, for example, if the assessor was culturally inappropriate.

Our members have highlighted compassion, empathy, professionalism, and respect as necessary attributes - they want someone who is willing to give them the time they need to explain and actively listen to them talk about information that might be distressing or highly intimate.

Assessors may need to de-escalate situations and manage challenging behaviours – so experience working with complex clients would be a distinct advantage. We would also expect that assessors were highly ethical, unbiased, and perceptive enough to know where they may need to ask for more detail or clarify their understanding.

Assessors should have to comply with a Quality Assurance Framework and abide by a Code of Conduct. Assessors should also undergo standard checks including Police Checks and where relevant Working with Children Checks.

We note that there may also be specific cultural considerations that need to be factored in when matching an assessor to a participant, for example, a female in some cultures may feel uncomfortable being assessed by a male assessor, it may be more culturally appropriate for an ATSI participant to be assessed by an ATSI assessor. It is preferable that participants from CALD backgrounds can access an assessor who can communicate with them in their own language.

During our research and consultations, one of the most commonly posed - and perhaps most pertinent – question regarding independent assessments was ‘how can the independent assessors be independent if they are being paid for by the NDIA?’.

As indicated by Synapse, the organisations have been engaged via tender, and will be contracted to the NDIA – with all the red tape and accountability that goes along with that.³⁴ Add to this concern that a person with multiple disabilities may be matched with an assessor only familiar with one type of disability – and it is a little wonder people are worried about the qualifications and expertise of these assessors.

Most critical to achieving quality outcomes this is applying a robust Quality Assurance Framework which all independent assessors would be expected to comply with. The second aspect would involve collecting data on participant experiences both in relation to specific assessors and across the scheme more broadly. We would see that are two aspects that should be reviewed including:

- the participant’s practical experience across the Independent Assessment – including issues such as how informed they were prior to the assessment, whether their access needs were sufficiently accommodated, whether the felt culturally safe, and

³⁴ Synapse 2020, *Synapse strongly rejects compulsory NDIS Independent Assessments*, <https://synapse.org.au/news/synapse-strongly-rejects-compulsory-ndis-independent-assessments/>, accessed 16/12/20

- whether the Independent Assessor complied with the Quality Assurance Framework; and whether the Independent Assessment accurately captured their functional capacities and whether this translated to an appropriate plan and funding.

People are concerned that assessors will not have the required qualifications or expertise to accurately “assess” their disability (or disabilities), and this will have huge ramifications for a person’s plan, should they miss out on essential supports and service. We suggest that this fear is justified, as the framework itself says that in some areas where thin markets exist, highly trained and specialised professionals may not be available or practicable to carry out the assessment.³⁵

While this is a reasonable assumption to make, it does beg the question – why go ahead with IAs? Particularly in regional, rural or remote areas where assessors with the required experience and qualifications may not be available?

We note that the Tune Review recommended that safeguards be put in place including a Quality and Safeguards Framework for Independent Assessors, and participants having the right to choose which NDIA-approved provider in their area undertakes the functional capacity assessment.³⁶

Recommendation 1:

That the NDIA postpones the implementation of independent assessments to allow for:

- *an assessment into the feasibility of the proposed tools in the context of choice and control for participants under the NDIS scheme*
- *the development of the Quality Assurance Framework*
- *a more thorough assessment of the structure of the proposed independent assessment process and*
- *the opportunity for additional input and consultation across the disability community.*

Recommendation 2:

As part the preparation for an independent assessment, require assessors to have pre-assessment contact with the participant to establish rapport, address any concerns that the participant might have and to ensure that the participant has all the information they need.

e) Appropriateness of assessment tools selected for use independent assessments to determine plan funding

The NDIA has chosen a suite of assessment tools to be used in the independent assessment process.

These tools can be found on the NDIS website³⁷, and include, but are not limited to, the World Health Organisation Disability Assessment Schedule (WHODAS) 2.0, Lower Extremity Function Scale, Vineland 3 and Craig Hospital Inventory of Environmental Factors (CHIEF). We are concerned that these tools are limited in scope and do not go far enough to capture all disability types. There is no indication from the NDIA how, or even if, the tools will be used to determine a person’s overall capacity – particularly for people with multiple disabilities.

Take for example, the WHODAS. Described as a “generic assessment tool”, a quick look at the questions shows that assessor is asked to rate the person’s capabilities using a sliding scale of 0 – 5, and it asks the person to consider the past 30 days in their responses. This is of great concern because a person’s abilities cannot be measure solely on the past 30 days.

In addition, a functional capacity tool is inappropriate for determining plan funding, as it doesn’t provide a holistic picture of the person.

³⁵ Ibid.

³⁶ Tune review, page 66 at 4:34.

³⁷ NDIS 2020, *The assessment tools in the toolkit*, <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-toolkit/assessment-tools-toolkit>, accessed 12/3/21.

The NDIS has stated that the assessment could take anywhere from 20 minutes to three hours, but this is not enough time to get to know a person and their goals and aspirations or capture all their informal supports.

As previously stated, our members, and members of MDNSW and SCIA who attended our consultation on independent assessments, are concerned that the process will remove the individualised nature of the NDIS – something that is at its very core, and what it was founded on.

The Government is arguing that the Productivity Commission always intended for independent assessments to be part of the process, however the Commission itself stated, in its 2011 inquiry report, that there was no perfect tool, and that until there is, the NDIS should endeavour to determine an appropriate suite of tools that can be used to assess access and eligibility.³⁸

This implies that several different methods should be used, whereas the information coming from the NDIS suggests that one assessment tool will be used, and more information may be sought where necessary – but this would be the exception not the rule.^{39, 40}

The NDIA states that the independent assessment will make sure that you get the right funding in your plan for your functional capacity, support needs and goals.⁴¹

But how will it ensure this? This is one area that we believe cannot be adequately addressed until independent assessments have become part of the process. There is just too little evidence to really understand the implications for planning decisions, including plan funding.

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

*“No one likes to be assessed. It’s an unnatural and stressful situation to put a person in.”
– person with disability at PDCN’s Independent Assessments Roundtable*

We suggest that there is at least three cohorts of people who would not be suitable for Independent Assessments. The first cohort would be people with very complex disabilities where there may be significant communication barriers or other extenuating circumstances which would mean that it was highly unlikely that an independent assessment could accurately determine their functional capacities – for example, if someone has experienced a catastrophic brain injury.

The second cohort of persons are those who have stable, permanent conditions where it is expected that there will be no change in functional capacity. Several of our members have expressed frustration at what they view as useless periodic reviews where their supports and funding remain consistent. More must be done by the NDIS to improve efficiencies across the assessment process – removing the requirement for assessments for people with stable functional capacities would work towards this.

The third cohort is people with intellectual or psychosocial disability. Feedback from our members and stakeholders has shown significant concern that for these people, independent assessments pose an incredible risk to their health and wellbeing. It would also increase the need for nominees, as some people (people with some intellectual disabilities, non-verbal, acquired brain injuries) will

³⁸ Ibid, note 17.

³⁹ Ibid, note 4.

⁴⁰ NDIS 2020, *Consultation Paper: Planning policy for personalised budgets and plan flexibility*, <https://www.ndis.gov.au/community/have-your-say/planning-policy-personalised-budgets-and-plan-flexibility>, accessed 14/1/21.

⁴¹ NDIS 2020, *Independent Assessments and your plan*, <https://www.ndis.gov.au/participants/independent-assessments/independent-assessments-and-your-plan>, accessed 12/3/21.

need assistance from parents or family to partake in the assessment. This will include a considerable human resource component that the NDIA does not appear to have considered.

"They say that we have choice and control and then they do this. This removes choice and control from us."

– person with disability at PDCN's Independent Assessment Roundtable

Participants who are already part of the scheme have often invested significant time and effort in establishing plans that they are satisfied with. They interpret the transition to Independent Assessments as overriding the efforts that they have already made to no tangible benefit. They view IAs as a way to cut costs.

"We have provided this information to the NDIS through our OTs [occupational therapists]."

– participant at PDCN's Independent Assessments Roundtable

"Blunt instrument to reduce funding. I'm terrified."

– participant at PDCN's Independent Assessments Roundtable

A number expressed that they see Independent Assessments as antithetical to the NDIS' core values of choice and control for people with disability – eroding their confidence in the Scheme as a whole. The current process is multifaceted and takes into consideration a number of elements, including informal supports, a person's goals and aspirations, and evidence from treating professionals. It takes an individualised view to access and planning – something our members feel they have worked hard for and would be removed by the introduction of IAs.

We suggest that independent assessments should not be mandatory, they should be included as part of a number of tools and recommend that this be included as part of the updated legislation.

Recommendation 3:

That the new legislation stipulates that assessments will not be mandatory, that for people entering the scheme, they will only be used as necessary (eg. when all other evidence provided is not sufficient) and, in the case of people already on the scheme, they will only be used as the need arises (e.g. in instances where it is likely that someone's support needs have changed dramatically).

Recommendation 4:

That people with stable, permanent conditions where it is expected that there is no change in functional capacity be excluded from the requirement to undergo an independent assessment until such time as their circumstances change.

Recommendation 5:

That the NDIS should have the discretionary power to exempt an individual from having to utilise an independent assessment as a mechanism for assessing functional capacity, should there be compelling reasons to do so, based on the individual's specific circumstances.

i) opportunities to review or challenge the outcomes of independent assessments

"Inability to challenge the assessment is extremely concerning."

– person with disability at PDCN's Independent Assessment Roundtable

At the time of writing this submission, the NDIA had also called for feedback on its yet to be finalised Access and Eligibility Policy with independent assessments, which PDCN made a submission to.

As such, it is unclear what opportunities participants will have to review or challenge a decision. The consultation paper and the IA Framework both indicate that there won't be any avenues to appeal the assessment itself – rather, a participant can appeal the decisions made on the basis of the assessment – including the plan budget. This has huge implications for a person's plan and plan budget.

People are concerned that the process does not recognise that people have “good” and “bad” days and that it is intimidating, highlighting that the language used – ie. calling it an “assessment” – is confronting and demoralising for people.

“No right of appeal either.”

- person with disability at PDCN's Independent Assessment Roundtable

PDCN is concerned that there are very few avenues to appeal and that, in fact, formal appeals will increase, because appealing the access decision or plan will be the only way to refute the IA.

As part of monitoring and evaluating independent assessments there needs to be a mechanism for participants to lodge complaints about Independent Assessments specifically. Currently we understand that participants can raise an appeal about decisions made as a result of an Independent Assessment report, but no mechanism has been described for complaints regarding the Independent Assessment process and this needs to be remedied. The NDIA should track appeals relating to decisions resulting from Independent Assessments and any complaints regarding the Independent Assessment process.

In addition, we note that the NDIA is developing a quality assurance framework and suggest that this should have been included in the access and eligibility policy consultation process, as a robust quality assurance framework is vital to delivery of effective independent assessments.

“You should be able to request a second one if you're unhappy.”

- person with disability at PDCN's Independent Assessment Roundtable

Recommendation 6:

That the NDIS establish a framework which allows participants to lodge complaints about the Independent Assessment process and seek appropriate remedies.

Conclusion

Independent assessments represent a major change for NDIS participants, and we share many of the scepticisms around whether switching to independent assessments will in fact lead to a more equitable distribution of supports and funding, redress inequities stemming from disadvantage, reduce appeals or resolve issues of patient bias.

In terms of addressing inequities resulting in supports and funding, we imagine that there will still be variations across the capabilities of independent assessors to accurately identify a participant's functional capacities – and in areas where there are limited numbers of assessors, for example, rural and regional areas, or where Independent Assessors are highly specialised or have particular skills, e.g. speak a community language, we may see similar pockets of disadvantage develop, not to mention backlogs and delays in assessments in areas where assessors are in limited supply – a situation that is currently avoided by the use of the participant's preestablished network of health professionals.

One of our biggest concerns is the many unanswered questions posed by the introduction of independent assessments. Participants are concerned that their introduction – with very limited consultation and only a small pilot, has been rushed, and goes against the core values of the NDIS – choice and control. Participants, and prospective participants, remain in the dark about the details

of independent assessments and what they will mean for access to the Scheme, and appropriate funding in the scheme.

PDCN members have also expressed concern that this is proceeding with very little consultation with the people it affects the most – people with disability. This is most blatant in that the NDIA had already begun the tender process before it announced independent assessments would be rolled out⁴², and then announced the winning tenders for the Independent Assessments three days after the consultation to the access and eligibility policy consultation closed, and a month prior to submissions to this inquiry closing.⁴³ The companies appointed are highly dubious to us, given their status as subsidiary companies of NDIS providers.

Given our scepticism around the capacity of independent assessments to result in positive changes to members, the strong push back we have heard across our membership as individuals who will be subject to the changes, and our concerns about the integrity of the tender process, we cannot endorse independent assessments as they are currently proposed.

We see Independent Assessments as a tool that could potentially complement and possibly even enhance the effectiveness of determining the supports and services that people with disability need - but we emphasise that PDCN does not support the proposal to remove the current system of relying on information from treating health professionals in preference of Independent Assessments.

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