



**PEOPLE WITH DISABILITY
AUSTRALIA**

**A voice
of our
own**

We contest the NDIA's justification for NDIS independent assessments

People with Disability Australia critiques Independent Assessments Submission 13, the National Disability Insurance Agency's submission to the Joint Standing Committee on the National Disability Insurance Scheme Inquiry into Independent Assessments 2021

**APRIL
2021**

About PWDA

People with Disability Australia (PWDA) is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation — and we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation. We help individuals by advocating for their interests, and groups through our systemic advocacy efforts.

We also encourage people to engage in self-advocacy. PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement. We employ many people with disability.

We have a vision of a socially just, accessible, and inclusive community, in which the human rights, citizenship, contribution, potential and diversity of all people with disability are recognised, respected and celebrated.

PWDA is committed to human rights and believes human rights are for everyone, regardless of race, religion, ethnicity, indigeneity, disability, age, displacement, caste, gender, gender identity, sexuality, sexual orientation, poverty, class or socio-economic status.

Our organisation founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

PWDA is a NSW and national peak organisation and founding member of Disabled People's Organisations Australia (DPO Australia) along with Women With Disabilities Australia, First Peoples Disability Network Australia, and National Ethnic Disability Alliance. DPOs are organisations that are led by, and constituted of, people with disability. We are a DPO and work as a disabled people's representative organisation, representing the interests of our members.

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We oppose the independent assessments proposal like dozens of other organisations

People with Disability Australia (PWDA) is one organisation among many who oppose the NDIA's independent assessments proposal.

We helped write a sector statement opposing so-called independent assessments, then [released it publicly](#) at the Every Australian Counts website.

That statement is found in Appendix A.

We were one organisation among 20 when we released the statement on 11 March 2021. Now we have been joined by at least 92 other organisations who also oppose the NDIA independent assessments proposal.

Our number had reached 112 organisations by 30 March 2021, and includes:

The 11 lead organisations in this campaign, including ourselves, are:

[Australian Autism Alliance](#)
[Australian Federation of Disability Organisations](#)
[Children and Young PWDA](#)
[Disability Advocacy Network Australia \(DANA\)](#)
[Every Australian Counts](#)
[First Peoples Disability Network](#)
[Inclusion Australia](#)
[National Ethnic Disability Australia](#)
[PWDA](#)
[Women with Disabilities Australia](#)
[Young People in Nursing Homes Alliance](#)



About this submission

PWDA welcomes this opportunity to critique the National Disability Insurance Agency (NDIA) submission the Joint Standing Committee on the National Disability Insurance Scheme's (NDISJC') inquiry into the proposed use of so-called independent assessments.

We note published [submission 13](#) was released as a joint submission with the Australian Government's Department of Social Services. While we note this connection, we will refer to this document as the NDIA submission.

PWDA's approach to this critique is to insert our views on the published document, in comment balloons.

We have used the same numbers as the NDIA's submission.

Below is our critique of the NDIA's submission on its proposal.



Independent Assessments



Australian Government
Department of Social Service



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

March 2021

The Department of Social Services
The National Disability Insurance Agency



Preface

The Department of Social Services (DSS) and the National Disability Insurance Agency (NDIA) welcome the opportunity to provide a submission to the inquiry of the Joint Standing Committee (JSC) on the National Disability Insurance Scheme (NDIS) into independent assessments.

[This submission provides a summary of the background and key reasons why independent assessments are being introduced, noting they are just one part of a broader reform program that will focus on the individual participant experience, achievement of outcomes, and ongoing service improvements.] [The submission also outlines how independent assessments will provide greater consistency in decisions about a person's functional capacity and the supports an NDIS participant is provided in their plans.]

[The intention to roll out independent assessments and introduce greater plan flexibility was originally announced by the Minister for the NDIS, the Hon Stuart Robert MP (Minister Robert), in November 2019. They represent a key part of the [Australian Government's plan to deliver on the last 20 per cent of the NDIS](#) and are an essential tool to ensure equitable, transparent and consistent outcomes and increase confidence in decision-making about a person's eligibility for the NDIS and their NDIS plans.]

Commented [PWDA1]: Details of the broad reform program, including details of draft legislation leaked publicly in February 2021, have not been available to people with disability, their families and representative organisations. People with Disability Australia holds serious concerns about proposed legislative and broader changes, including the proposal to introduce independent assessments. PWDA's members report widespread anxiety, fear and tension about the plan to introduce independent assessments. While recognising that the draft legislation was not a final draft and may not be indicative of government's full intentions, academics, advocates and stakeholders have raised concerns that the plans outlined in the draft would jeopardise the future of the National Disability Insurance Scheme and undermine the rights of disabled people.

Commented [PWDA2]: PWDA does not believe that 'ensuring greater consistency in decisions about a person's functional capacity' will be a key element in ensuring they have the *right* supports. The proposal to adopt a deficit-focused model (that is, based on what people cannot do) rather than a goals and outcomes-focused model (a model which is centred on a person's aspirations and rights) is contradictory to a rights-based approach. In addition, determining a funding allocation prior to determining what goals and aspirations a person has during a planning meeting does not allow for the vast range of experiences, cultures, ages and desires that are reflected within usual human diversity. Nor does it allow for a person-centred approach, one of the key elements of the landmark NDIS scheme.

Commented [PWDA3]: 'In the September 2020 NDIS independent assessment evaluation report, the government suggests that 'assessment scores of up to 8% of participants suggested functioning within the typical range for their age.' PWDA holds deep concerns about this statement, given that there is no publicly available data about the trial, nor a comprehensive evaluation. Given that the same 8% of participants have comprehensively proven to the NDIA that they have a permanent disability and that they require significant help every day, this statement is worrying. If 8% of current participants were to be rejected from the NDIS on the basis of the use of untested and controversial standardised assessment tools, 34,400 disabled Australians would be displaced from their existing supports. Proposing to further disadvantage the remaining Australians who have not yet accessed the scheme is an untenable proposal. There are existing problems with accessing the scheme – current AAT statistics are not reflective of the number of people who do not try to fight an access decision, cannot access advocacy because of long wait times or who experience undue influence from the ²NDIA. In addition, existing State and Territory schemes which have been collapsed since the inception of the NDIS no longer provide support to those who would potentially become ineligible. ¹ <https://www.ndis.gov.au/media/2686/download> ² 90 per cent of the cases may be subject to undue influence by the NDIA – <https://probonoaustralia.com.au/news/2019/10/the-administrative-appeals-tribunal-affirms-less-than-2-of-ndis-decisions-appealed-by-participants>



This submission provides further information to clarify the intent of independent assessments and address potential misconceptions.

A reform of the scale and size of the NDIS comes with both opportunity and challenges. To effectively address these challenges and ensure a more consistent flexible and equitable NDIS, OSS and NDIA are committed to actively seeking feedback on independent assessments and other reform proposals through an ongoing and comprehensive consultation program.

These changes will mean that the NDIS will more closely resemble the model originally recommended by the Productivity Commission. They will also help deliver an NDIS that empowers participants, is easier to understand and provides greater flexibility, choice and control to improve outcomes for all people with disability, their families and carers.

Commented [PWDA4]: The consultation program that the NDIS has undertaken has been advisory, rather than consultative. PWDA is a co-signatory of the *Disability sector statement on the Australian Government's planned reforms to the National Disability Insurance Scheme (NDIS)*, which rejects the introduction of independent assessments. The sector statement is found here: <https://everyaustraliancounts.com.au/ndis-sector-statement>

Commented [PWDA5]: PWDA is concerned about the statement by the NDIA that asserts that there will be greater scheme flexibility. The issues which have been cited around a loss of flexibility by advocates, people with disability and their families include the following:

- changes to transport funding methodologies mean that people will not be able to use their transport funding creatively and in cost effective ways (for example, paying a neighbour petrol money to provide transport in a remote region where there is no public transport or support available) and may not be able to use it because of poverty-related issues
- proposed 'rollover' of funds periodically does not allow adequately for changing circumstances
- plans to remove the concept of reasonable and necessary in the draft legislation means that supports will be narrowly defined and will reduce existing supports
- plans to grant the Federal Government extraordinary powers means that mainstream supports in states and territories may become overloaded because of refusal to provide support
- the proposal to introduce an algorithm which determines funding through untested assessment tools and a deficit-focused assessment process will unfairly restrict access for participants and provide less funding, especially when combined with the proposal to hold a planning meeting only after the assessment has been completed.



Background:

The NDIS was envisaged almost 10 years ago in the Productivity Commission's 2011 Report on Disability Care and Support. The Productivity Commission produced a set of recommendations, which provided the foundations upon which the NDIS was built. As the NDIS continues to grow and mature some of the original recommendations of the Productivity Commission have been reinforced by subsequent reviews and inquiries, including the 2019 Independent Review of the *National Disability Insurance Scheme Act 2013* (the NDIS Act) by Mr David Tune AO PSM (Tune Review).

The NDIS rollout and implementation challenges

The NDIS officially began on 1 July 2013 with trial sites in four regions across the country. The trial period ended in 2016, when national rollout commenced.

At 30 September 2016 there was just over 37,700 participants in the NDIS. By 31 December 2020 there were over 432,000.

The scale and pace of rollout has been highly ambitious. The clear focus up to now has been on creating a system where around 500,000 people are provided with individual funding, replacing block funding of organisations, with complex transitional arrangements across eight different state and territory systems. This has been challenging, transition has taken longer than originally planned, ensuring eligible Australians from state and territory disability systems are supported to access the NDIS while providers make the transition from certainty of funding and clientele to providing an expanded range of services and support in a competitive market to individuals who can choose what they want and from whom they purchase it. In addition to transitioning the many people previously supported through state funded services and some Commonwealth funded services, around 200,000 people are receiving supports for the first time.

Commented [PWDA6]: PWDA believes it is of concern that the Tune Review has been used to carry out these measures against the direct recommendations of people with disability, their families, disability organisations and allied health professionals.

Commented [PWDA7]: PWDA believes there are significant market gaps within the NDIS market. People in regional and remote locations report that they are unable to use their funding because there are no providers within their area. Others in city areas report waiting lists of up to eighteen months. The State of the Disability Sector report¹ (NDS, 2020) reports that the sector is operating 'well short of full strength'. Fifty percent of very small providers are just breaking even or making a loss; estimates say that the disability sector will need to double in size in order to support the scheme at full rollout. If independent assessments remove allied health graduates from the existing market, disabled people face crises around already-thin markets and access to supports and services. National Disability Services, the peak body for disability service providers, opposes independent assessments.
¹ <https://indd.adobe.com/view/5d704c30-db3a-49d3-9d5b-0c788c1e21a9>



The recent focus has been on resolving outstanding implementation issues substantially improving timeliness of access and planning for participants, clearing backlogs, while also assisting providers to expand and develop their workforce and introducing national approaches to enduring quality and safety. For example, as at 31 December 2020, 98 per cent of reviewable decisions were completed within 90 days, compared to 60 per cent in December 2019, 98 percent of first plans were approved for participants aged seven and above within 70 days compared to 64 per cent in December 2019, and 92 per cent of complaints were closed within 21 days compared to 58 percent in December 2019.

It has been a remarkable transformation in a few short years, but the development of the scheme is not yet complete. More people will be supported through the scheme, and further changes are required to resolve inequities in access and planning outcomes, as we work towards a mature and financially sustainable NDIS which will benefit around 500,000 Australians with permanent and significant disability by 2023.

DSS and the NDIA recognise the need to make NDIS processes simpler and more straight forward and remove barriers to positive participant and provider experiences.

A fundamental design feature of the NDIS

The quality of information underpinning decisions as to who is eligible for the NDIS and the amount of funding they receive for supports is fundamentally important to the success of the NDIS.

This was recognised in the 2011 Report of the Productivity Commission, which recommended that the NDIS should provide *'individually tailored supports based on the same assessment process, certainty of funding based on need, genuine choice over how their needs were met (including choice of provider)'*.

During transition, people receiving specialist supports through state, territory and Commonwealth programs were designated as eligible for entry to the scheme. These were expected to be the significant majority of people coming into the NDIS during the transition. In some cases, the quality of data provided by governments to support the transition of these people was inadequate to allow the NDIA to make consistent decisions about a person's eligibility for the NDIS and the supports in their plans.

Commented [PWDA8]: PWDA highlights the Productivity Commission report was rebutted by a number of submissions around the concept that existing providers may use 'sympathy bias' to falsify or modify reports. Given that allied health providers use standardised testing tools, as well as specialist skills for their individual industries, there is no evidence that this has ever been a phenomenon and it is not evidenced in literature or research.

Commented [PWDA9]: PWDA maintains that the most appropriate clinician to assess a person's level of support and functional assessment is their own specialist or general practitioner. In addition, disabled people should not be subjected to ongoing assessments unless there is evidenced need for this assessment – for example, if the person requires a new piece of equipment or needs to demonstrate the need for a new type of therapy. In order to prove that we are eligible for the NDIS, we must determine that we are permanently disabled and need care and support every day – constantly reiterating that need is traumatising and causes distress to people who want to focus on what they can do, not what they cannot. There is no proposal by government to offer assistance with diagnosis – we suggest that access to diagnosis and a Medicare line item being implemented to assist existing practitioners with necessary assessments would be a far more acceptable solution.

Independent Assessments



Australian Government
Department of Social Service



In addition, with over 212,000 participants receiving supports for the very first time at 31 December 2020, almost half of current NDIS participants have been required to source their own evidence of their functional capacity, which has contributed to inconsistent decisions based on the quality of the evidence provided.

This has meant there is a lot of variability in the amount type and quality of information people assemble. Furthermore, they have to meet the expense of this themselves, or rely on the good will of the professionals and support services from whom they assemble their information. This has also meant those with greater resources (time, money, the support of family) or a better capacity to understand and navigate the complexities of assembling the information can have an advantage over those with fewer resources or who find the process challenging, confusing and frustrating. These experiences can challenge the credibility of the scheme at the outset of a person's experience of it.

Commented [PWDA10]: 'Inconsistent decisions' are based on the standard of literacy of a person, their socioeconomic status and ability to afford diagnostic assessments (not proposed to be covered by the NDIS) and the availability of assistance in their area. But they are also based on the life of the person and the type of support that they need because of their job, location, study, family circumstance or life goals. NDIS plans were never intended to be 'consistent' or have a 'cookie cutter' approach – they were intended to reflect the full diversity of human life.

Commented [PWDA11]: The NDIA states there are inequities for those with fewer resources, including those with less time, money or the support of family. PWDA agrees with this statement; however, we believe the inequities will be highlighted and emphasised with the introduction of independent assessments, especially for those experiencing double disadvantage because of their cultural background or socioeconomic status. Independent assessments present an additional barrier for people to navigate – our members report that the process will be dangerous, inaccessible and potentially harmful. The untested standardised assessment tools have not been tested for use on disabled people to determine funding levels and have not been tested in combination with each other. In our survey in October last year, members reported heightened anxiety about having to navigate yet another process, especially with unfamiliar practitioners who may not be familiar with their disability, family or cultural circumstance or life.



Changes should be made to make it easier for people to provide the necessary information, with greater standardisation of the information required, while minimising the cost to the individual. These changes should align with the original recommendation from the Productivity Commission, that “[a]ssessors should ... be independent of the person being assessed to reduce the potential for sympathy’ bias”. The PC report recognised that health professionals who have been supporting an individual are often placed in a difficult position when asked to undertake an assessment that relates to a person’s eligibility for NDIS. The potential for over-stating of an individual’s needs by a health professional who has known a person for a period of time, even if it is unintentional, poses a risk for appropriate and equitable decision making.

Commented [PWDA12]: The rationale for “sympathy bias” is a term which originated in the 2011 Productivity Commission report and which was based on a plausibility argument rather than a problem based on evidence of the prevalence of any sympathy bias affecting the scheme. There have been no studies done by the NDIA in this area. The NDIA referred to a fifteen-year-old study which investigated whether assessment tools obtained different results for different purposes and which found that there were significant overestimation of support needs when raters know they are being used for funding purposes.¹ However, the study² investigated only 29 people with intellectual disabilities, using a testing tool which is not proposed to be used by the NDIA. In terms of risk, there is far more risk – for both positive and negative rater-bias – with using unmatched clinicians who are working outside their specialist area with unproven assessment tools. There is also an increased risk of potential fraudulent claims, state some groups, because of the availability of the assessment tools and the history of how similar schemes have worked – and not worked – in other countries in the past. In the UK, ATOS, a private outsourcing company, ran independent assessments to determine job capacity across the UK. One hundred and eighty-six people a month who were declared ‘fit to work’ died. Information about the assessments was shared broadly. This year, the UK government is carrying out a trial to investigate if they can run their own assessments. Lawsuits³ were started against the UK government, ATOS and the makers of the assessment tools by bereaved family members and people with disability. There is also the potential for inexperienced assessors to be more likely to rely on family members to provide information, and according to the NDIS, those family members will be likely to paint the worst picture. In recent weeks, news was released that the companies who were successful in the independent assessment process are working for organisations who are owned by bigger organisations who provide NDIS supports. Those organisations could potentially be compromised by vested interests, given they will be able to vie for provision of services with bigger plans.

¹ <https://research-repository.griffith.edu.au/rest/bitstreams/f2db93be-511d-4ca7-9291-8015f39e0389/retrieve>

² <https://pubmed.ncbi.nlm.nih.gov/16954093>

³ <https://dpac.uk.net/2013/04/what-people-need-to-know-about-atos-assessments>



The Tune Review reinforced the importance of implementing more equitable assessments to support improved national consistency in decision-making. The Tune Review noted that inconsistencies and burdens experienced by people with disability in gathering information have contributed to inconsistency of access and planning decisions, resulting in inequity for people applying for and using the NDIS. The Tune Review recommended implementing independent assessments as a way to mitigate the current barriers that exist for people with disability seeking to navigate the NDIS which have led to frustration and reduced trust in the NDIS from the perspective of people with disability, their families and carers and others who support them.

Commented [PWDA13]: There is no proposal to increase availability of access to diagnosis, and people with disability will have diverse evidence to provide, given that the evidence is based on previous levels of support. For those who have been well supported in the past, it is easy to collect and provide documentation. For those who are in regional and remote areas with no access to diagnosis or therapy, provision of evidence will be difficult. PWDA maintains that there should be remedies available to remedy these inequities but they should not be mandatory, nor potentially punitive, nor carried out by people who are not chosen by or familiar with the person they are assessing or diagnosing.

Commented [PWDA14]: Independent assessments will not mitigate the current barriers for people seeking to navigate the NDIS.

What has been proven to reduce barriers to entry is:

- accessible and clear information
- access to diagnosis
- more accessible systems, informed by a good co-design process with people with disability and their families
- access to well-funded and readily available advocacy
- fast processes and accessible complaints mechanisms.



The Tune Review also reinforced the intent of the Productivity Commission’s recommendations by highlighting that independent assessments should be used to promote independent outcomes and provide national consistency in assessment approaches. The Government will roll out independent assessments to ensure the scheme is implemented as envisaged.

Importantly, the idea of independent assessments is not new. Evidence of a person's functional capacity has always been part of the NDIS and is embedded in the NDIS Act as being a key input to decision making. In this regard, the supports provided under the NDIS have always been based on a person’s functional capacity to undertake activities of daily living rather than on the presence of an underlying diagnosis, condition or injury.

Currently people with disability seeking access to the NDIS are required to source their own reports about their functional capacity. These reports are used in NDIS planning meetings with an NDIS planner not previously known to the participant, who determines the participant's functional capacity and associated support needs. Where a participant is unable to provide evidence of functional capacity, the NDIA completes internationally recognised general standardised functional assessments with participants or their representatives.

The current approach results in inconsistencies and variability in the scope, type and quality of information provided, and frustrations for all concerned, where clarifications are sought and further information has to be obtained, creating uncertainty and delaying decision making.

Commented [PWDA15]: The Australian Government states that the scheme will be implemented as envisaged, but this is incorrect. The scheme was never intended to be a deficit-focused scheme – it was always intended to be a rights-based scheme which held people with disability at the centre of the NDIS.

The NDIS is intended to uphold our rights, which include:

- to be free from violence and abuse
- to get the right health care and any personal support we might need to live a good life
- to choose our own support for living and work
- to get the right information that we need to make a decision
- to make decisions and be listened to with support that we choose
- to get an education
- to have access to sport, leisure and community life
- to say where we live, who we live with and who we have relationships with.

PWDA believes that unless our lives, and the rights articulated above, are front and centre of the conversation and are a holistic part of the planning and funding process, the scheme will not be as envisaged; it will be the same as the redundant and inequitable past schemes that we fought against and replaced with a National Disability Insurance Scheme.

Commented [PWDA16]: The statement that the supports provided under the NDIS are based on functional capacity is incorrect – that is only part of the planning process and how the scheme works. This proposal is solely deficit based – it proposes to look at what we cannot do rather than looking at what we can do, what we want to do, what our lives involve and what our aspirations are.

Commented [PWDA17]: The proposal to use general standardised functional assessments is inherently problematic. The NDIA’s own document states that some tools have not been tested with Aboriginal groups, nor groups from culturally and linguistically diverse backgrounds (for cultural appropriateness). The tools have not been tested in combination with each other. Importantly, they are designed to be used by practitioners who are familiar with the type of disability that the person with disability has, and who hold specialist qualifications in that area. To use unqualified or unskilled people who have worked in disciplines outside of the relevant field is dangerous and has the potential to cause harm to participants. PWDA strongly recommends against this course of action.

Commented [PWDA18]: The current approach may create inconsistencies and variability, but the onus should be on the NDIA to provide people with disability, their families and allied health and medical professionals clear and accessible information to ensure that they are able to access the scheme. The NDIA should ensure its communications, requirements and expectations are clear to people with disability, their families and treating practitioners and allied health professionals.



Participant feedback on the current approach indicates concerns including:

- lack of clarity about the kinds of evidence required by the NDIA to make decisions;
- assessors having varied levels of understanding about functional capacity and the impact of disability on activities of daily living;
- a range of tools being used that are not all fit for purpose;
- different levels of detail being provided in assessments;
- assessments being completed at different times, so information may be out of date or circumstances may have changed;
- a level of inconsistency and subjectivity in assessment information;
- assessments being a costly and time consuming burden for families, estimated to cost in aggregate around \$130 to \$170 million a year, making them out of reach for many; and

Commented [PWDA19]: There has been no information provided by the NDIA to assessors to assist with this task. SCOPE and RACGP have authored their own report-writing toolkits; outside of those resources, there remains little to no useful information provided by NDIA for the purpose of helping people understand evidence required from assessors.

Commented [PWDA20]: The range of tools proposed to be used by the NDIA are not fit for purpose – numerous issues have been raised by medical professionals about using them in the ways planned.

Commented [PWDA21]: PWDA understands this cost is predicated on the total cost of diagnosis, as well as increased stated requirement for functional impact assessments by the NDIA. This has been cited by the NDIA but has not been evidenced.



- assessments being influenced by where a person lives or their ability to describe their circumstances and needs.

The introduction of independent assessments from 2021 is central to addressing these challenges. They will ensure all people with disability are supported to gather evidence of functional capacity. They will also reduce current pressures on NDIA Partners in the Community, who will refocus on their originally intended functions, ensuring that people are appropriately supported to access supports and services in their community and implement their plans.

Independent assessments will also ensure participants receive a more flexible plan budget based on their functional capacity to access the services they need and help pursue their individual goals and aspirations.

The outcomes of the participant's independent assessment will inform their personalised budget. This budget will reflect the expected costs of providing a reasonable and necessary package of supports for a participant with a similar level of functional capacity, support need and environmental context. This budget can be used by the participant to pursue their individual goals. The budget is not derived from those goals, though the budget will reflect the likely costs associated with important life stage transitions, such as leaving the family home for the first time or pursuing employment. This means that in the future a participant's plan will no longer be based on individual decisions about each and every support. This in turn means that people will be able to use their funds more flexibly – a critically important feature of the basic design of the NDIS.

Commented [PWDA22]: Assessments should be influenced by where a person lives, by what their lives looks like, by what they require and by what kind of support they need in their day-to-day lives, as well as their goals and aspirations. There are other factors which have not been investigated by the NDIA, including negative bias toward families with low socioeconomic backgrounds or for people of colour/Aboriginal people.

Commented [PWDA23]: There is no indication that the plan budget will be more flexible, nor that it will be more easily used, especially if section 34 of the *National Disability Insurance Scheme Act 2013* is essentially removed to narrowly define the concept of reasonable and necessary.

Commented [PWDA24]: This is essentially a reversal of the NDIS as we know it and a return to the old, deficit-focused systems that we fought against. The outcomes of a rushed assessment using standardised measurement tools should not inform our 'personalised budget' – in the NDIS, funding is not dictated by cost but by goals and aspirations. The entire principle of the scheme is based around returned investment, that disabled people and their families will be able to equally contribute to the economy and that costs will not be shifted, that people will be supported to work and that the scheme will eventually pay for itself.

Commented [PWDA25]: Predicting "important life-stage transitions" is difficult or impossible for people with disability, as our life-stage transitions differ immensely from those of other people. For example, school extends to Year 13, and disabled people often stay at home for many years because of limited availability of housing and our opportunities to take up jobs are limited or vary wildly. We often experience drastically changed life circumstances with disruptions to informal care and support. Each diagnostic group has different life transitions which may or may not reflect the same transitions as non-disabled people. PWDA is unaware of any comprehensive studies that have been carried out in this area around life trajectories.



People making their own decisions about what supports they obtain and from whom is fundamentally empowering. Under the current approach which tends to seek to identify each and every support a person requires and attach a sum of funds to that, the result is a detailed and inflexible plan which is often contested in its preparation as people seek to make the plan comply with the supports they wish to purchase. It has also required NDIA delegates to make detailed and often relatively subjective decisions on plan inclusions and exclusion that are or are not 'reasonable and necessary'. In this way the process of arriving at the detailed plan and associated funding has become less empowering and more constraining of the choices that people can then exercise in the use of the fund allocated. Stepping away from plans based on itemising every individual support is essential to giving participants greater flexibility to use the funds they receive as they see fit. There will still be a need to identify some particular types of support or high cost supports, but overall people should have greater flexibility to use the funds as they wish for the supports they need'.

Participants, their families and carers are best placed to make decisions about what supports they need to pursue their goals. At present the goal setting process for participants is restrictive and defined through the planning process. The introduction of personalised budgets will mean that, rather than negotiating and agreeing on each individual support needed to help them pursue their goals, participants can focus on how to best utilise their community supports, mainstream services and NDIS funding to pursue their goals and aspirations. The publication of participant decision guides and accessible information on best practice evidence will further support participants and their representatives to have greater choice and control over goal setting and attainment.

Commented [PWDA26]: There is no use having increased flexibility if the person does not actually have any money to pay for services and supports.

Commented [PWDA27]: A great deal of money has been already invested in Information Linkages and Capacity Building (ILC) funding and information guides about navigating the current process. Changes to this will be disruptive and there is existing evidence that independent assessments will not result in the best outcomes for people with disability.



The independent assessment framework and tools:

Prior to and since independent assessments were first announced in 2019, the NDIA has been conducting in-depth consultation to determine how to give effect to the intent of the Productivity Commission's recommendation and lay the foundations for a new approach to assessing a person's functional capacity. This work has been undertaken in close collaboration with experts in the sector to ensure it reflects best practice.

The Independent Assessment Framework, released in September 2020 ([Independent Assessment Framework NDIS](#)) provides further information on the rationale, principles and origins of the assessment framework including how it is underpinned by the International Classification of Functioning, Disability and Health. More than 100 recognised and standardised tools were assessed in developing the assessment framework to ensure they:

- are disability-neutral, so can be used across all disability-types;
- assess function rather than impairment;
- are questionnaire-based, to avoid capturing a person's moment-in-time function, for example on a 'good day' or with an unfamiliar assessor; and
- are accurate and reliable.

The approach and the tools to be used have also been endorsed by leading Australian academics:

“The [independent assessment] framework is consistent with international best practice. It has great potential to increase the accuracy of assessment, which is a critical foundation in determining the most appropriate supports for each individual.”

Professor Andrew Whitehouse, Autism CRC and Telethon Kids Institute, and Professor of Autism Research at The University of Western Australia.

“[The NDIA] have outlined a framework on which to build a fairer and more consistent disability assessment- to enable the rights of people with disability to participate across society. This diagnosis-neutral framework combines both the need to evaluate capacity and the determining role of the environment in helping or hindering participation.”

Dr Ros Madden AM, University of Sydney Honorary Research Fellow, University of Sydney and Nick Glozier, Professor of Psychological Medicine, University of Sydney.

Commented [PWDA28]: PWDA has refuted this argument and rejects the idea of independent assessments. See our perspective in the disability sector statement: <https://everyaustraliancounts.com.au/ndis-sector-statement>



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"The new functional capacity assessment framework by NDIS aligned to the International Classification of Functioning will undoubtedly enhance the development of effective programs matching each individual's functional level and needs, thereby optimising outcomes."

Valsamma Eapen, Professor and Chair of Infant, Child and Adolescent Psychiatry at the University of New South Wales, and Head of the Academic Unit of Child Psychiatry, South West Sydney.

Further information about independent assessment framework and implementation arrangements are set out in a number of information papers released by the NDIA.

These include:

- [Independent Assessment Framework](#), which explains the basis for the NDIA's move to independent assessments;
- [Independent Assessment Toolkit](#), which outlines which tools will be used during an independent assessment, the rationale for their selection, advice about the appropriate circumstances for their use and how they align with the International Classification of Functioning, Disability and Health; and
- [Evaluation of the First Independent Assessment Pilot](#), which summarises the lessons learned from this pilot in demonstrating the benefits of independent assessments and the suitability of the selection and scope of tools used for the purposes of access and planning decisions.

Commented [PWDA29]: The pilot does not provide the questions asked, the methodology nor details of how the tools were approved for ethical use on humans. The pilot report is also based on a small sample size.



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Our ongoing commitment to communicate and consult:

Once fully implemented, independent assessments will change how people with disability experience the NDIS. They will be paid for by the NDIA to ensure all people have equitable opportunity to access the NDIS and to be supported by a budget that meets their functional needs.

Independent assessments will also mean that the way a participant 's plan is built will change. From late 2021, instead of creating a plan that has funding based on individual items or supports, participants will receive an overall budget so they can choose the supports they receive. Planning meetings will be more focussed on the best way for individuals to use their plan to pursue their goals. Participants will know the value of their likely budget ahead of the planning meeting so they can start to plan how they can best use these funds alongside any mainstream, community and informal supports available.

As with any change, it is understandable that people will have questions or feel uncertain. Not surprisingly some aspects of these changes have caused some uncertainty and apprehension for some people.

In keeping with the Government's commitment to ensuring people with disability are at the centre of the NDIS, DSS and the NDIA will continue to openly communicate and share information in a variety of accessible formats, particularly to address misconception or to correct misinformation.

The NDIA is also committed to actively seeking feedback on the implementation of independent assessments and all other service improvement initiatives through a continued and comprehensive national consultation program.

To facilitate this, the NDIA released three consultation papers in November 2020 inviting people with disability, their families and carers and the entire sector to have their say on how the changes will be delivered:

- [Access and eligibility policy for independent assessments;](#)
- [Planning policy for personalised budgets and plan flexibility;](#) and
- [Supporting young: children early, to reach their full potential.](#)

Independent Assessments



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In parallel, the NDIA held over 170 virtual and face-to-face public and stakeholder events and sessions to be delivered between November 2020 and February 2021 to inform participants, family members, carers and the broader public of the intent of these reform and seek feedback on their implementation.

The NDIA consultation processes closed on 23 February 2021, with over 700 unique submissions received in response to the three papers. Following consideration of the submissions received, the NDIA will share more information about what people said during consultation.

Commented [PWDA30]: None of this information has been made public. The NDIA appointed those who tendered two days after 700 submissions were received, making it clear that the process would not be informed by the feedback from people with disability and their families.



What we have heard so far:

The NDIS is precious for the people it supports. It is new and completely different in concept than previous ways in which people with significant and permanent disability received what supports they could. Understandably, there is concern that any changes to this crucial new development for people with significant and permanent disability may potentially result in fewer people, receiving less support, with less power to make their own decisions.

That is not what is proposed under these changes. [The original Productivity Commission report estimated that an NDIS would support about 411,250 people at a cost for supports of about \$12.82 billion per year by 2018-19. In 2017, a Productivity Commission study of NDIS costs estimated that the NDIS would support 476,000 people at a cost for supports of \$21.84 billion. This financial year the NDIS is budgeted to spend \$21.72 billion on supports for an average across the year of around 422,000 people, and next year estimates for the scheme expect expenditure on supports of \$23.8 billion for around 480,000 people by the end of that year. The Australian government has been clear that it expects the scheme to grow to support around 500,000 people, and together with states and territories has provided for expenditure on participant supports to exceed \$24 billion by 2022-23. The scheme is on track to be more generous than originally conceived in terms of both the number of people supported, and the amount of support provided.]

Nevertheless, DSS and NDIA acknowledge there is still work to do to design and implement changes to improve the scheme to achieve what it was established to do. We are committed to working with participants and the disability community to get these changes right.

While the implementation arrangements for independent assessments are yet to be finalised, the DSS and NDIA wish to directly address some of the key questions and areas of concern raised to date:

1. Qualifications and cultural awareness of independent assessors.

Independent Assessors will be engaged by the NDIA to conduct assessments based on internationally recognised, evidence-based and consistent tools to provide a current and complete assessment of a person's functional capacity including the impact of their environment. Assessors will not be employees of the NDIA.

Commented [PWDA31]: The NDIA have repeatedly said that the independent assessments proposal was not about cost, so it is interesting to read this. There is no evidence available about the costs of previous schemes that were state based, and no information how much states and territories are now paying in the absence of a working NDIS.



Assessors will:

- have culturally safe approaches suitable for Aboriginal and Torres Strait Islander people and take into account requirements for people from culturally and linguistically diverse backgrounds;
- have the right skills, experience and training to support a person's disability needs; and
- be drawn from an Independent Assessment Panel which is being established by the NDIA through an open and competitive tender process.

Independent assessments will be carried out by trained experts, for example occupational therapists, physiotherapists, clinical and registered psychologists and other health and allied health professionals. While the output from an independent assessment will be consistent, the process by which it will be derived will take into account the needs of individuals.

Participants will also be able to be matched with an assessor who speaks their language. If this is not possible an interpreter will be provided. People with disability will also be supported to indicate their preference for how the assessment is undertaken if there are particular cultural reasons. To the extent possible, the NDIA will work to ensure these preferences are met.

2. Choice of independent assessors.

Independent assessors will be drawn from an Independent Assessment Panel. For most people with disability, there will be a number of approved assessors across Australia, ensuring that people will be able to access an independent assessor, no matter where they live, including regional and remote areas. This will mean that as much as possible, people will have choice about who they work with to assess their functional capacity and inform decisions on their access request or development of their plan.

The NDIA is currently finalising the evaluation of potential providers to be on the Independent Assessment Panel. Further information about the Independent Assessment Panel will shortly be available on the [NDIS website](#).

Commented [PWDA32]: The NDIA's own document says that the tools to be used are not culturally safe. There is no information about cultural safety for Aboriginal and Torres Strait Islander people – and one of the organisations appointed to conduct the assessments is advertising for new graduates, who are unlikely to have strong skills in working with proper cultural safety and sensitivity.

Commented [PWDA33]: There is no matching of disability type to specialist support type. The open and competitive tender process has been taken up by three major organisations and several subsidiaries, who are providing services in different areas.



3. Timeframes for assessors to conduct independent assessments.

There will be no time limit on assessments and they may be conducted over one or more days. The purpose of the assessment is to accurately assess the person’s functional capacity, as well as the environmental factors across their life. They will also involve family and carers in the process to build a complete picture of the person’s needs and how the NDIS could support them. Individual circumstances will always be taken into account.

People with disability can also choose to bring a trusted support person who knows them well to their assessment such as a family member, carer, support worker or health professional. People with disability can also choose if their support person is there for the whole time, or just for parts of the assessment. They can choose where the assessment takes place and it will be free – as it is paid for by the NDIA.

4. Breadth of assessment tools.

Independent assessors will use internationally recognised, evidence-based and consistent tools to provide a current and complete assessment of a person’s functional capacity. The assessment tools used during independent assessments will be aligned with the World Health Organisation’s International Classification of Functioning, Disability and Health, and the activity domains described in the NDIS Act. These are communication, social interaction, learning, mobility, self care and self-management.

This framework has provided the foundation for the [selection of assessment tools](#) to be used in independent assessments, and are set out in the NDIA’s [Independent Assessment Framework](#).

Commented [PWDA34]: The independent assessments tender says that there will be a time limit placed on assessments and that reports will be completed, along with assessments, in between one and four hours. At Senate Estimates in recent weeks, the cost of the assessments was outlined – it is approximately six hundred dollars per person. A provider will not spend two days on an assessment for this cost and the agency are paying a fixed amount per assessment, not per hour.

Commented [PWDA35]: The CHIEF assessment does not capture goals or environmental factors outside the home. It is not suitable for determining funding levels, like the other tools.

Commented [PWDA36]: Many of the people PWDA supports do not have family or carers and their workers may have varying (or biased) levels of information or opinions about the person. It is not an accurate determination of funding need to ask a third party, especially without regard to the privacy and dignity of the person with disability, to provide an opinion about the person’s abilities or needs. A disabled person should have their will and preference taken into consideration and supported decision making should be implemented to assist someone independently when they require support. There is a risk of abuse and/or harm here when someone may experience caregiver violence if a person is removed from support by a substitute decision making providing information via an independent assessor to the NDIA.

Commented [PWDA37]: Many people do not have a person in their life who can attend, or not all parts of their life are known to one or two persons. Nor should they be.

Commented [PWDA38]: The tools have not been proven to work in conjunction with each other, nor are they proven for use to determine funding levels.

Commented [PWDA39]: It is of great concern that the proposed legislation apparently seeks to redefine developmental disability in this way and to exclude neurological and intellectual disabilities. When this is taken into consideration along with the discarding of additional disabilities via operational tools (the LAC checklist specifically asks for only a ‘primary disability’ to be taken into consideration) there is great risk that people will be undersupported or not supported at all.



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5. Standard approach to capture individuals' needs.

The suite of independent assessment tools have been selected to ensure they are disability neutral and are focused on functionality, so they can be used across all disability-types.

The tools also seek to ensure that the impacts of all disabilities are well understood where a focus on the diagnosis or disability may not identify all of the ways the disabilities affect a person's life.

Commented [PWDA40]: This is not what has been reported to us by academics, people with disability or professionals. For example, one long-term member has a disability which causes her arms to be very short – she has to wash her hair with her feet. There is a lower limb assessment tool, but no upper limb assessment tool. The range of support needs that she has do not fit any of the tools and they would not capture her unique needs, which include caring for a child with disability.



Independent assessments are designed to capture a person's functional capacity as well as the environmental factors that impact on their ability to live an ordinary life without making assumptions based on disability or diagnosis, including people who have complex, rare or multiple disabilities.

While there will be greater consistency between plans individual circumstances will always be taken into account. The NDIA's key priority is to accommodate individual difference while implementing consistent information gathering protocols and requirements, and ensuring the tools work equally for everyone.

6. Protecting people with a disability and those who support them.

The Government's top priority for these reforms is to ensure the independent assessment process works for all participants. Independent assessments will be delivered in a tailored way to overcome barriers for all participants, including those with complex needs. The NDIA is committed putting processes in place to ensure all people with disability are supported to fully and safely complete an independent assessment. Participants can choose where to undertake their independent assessment, for example at home or by video call, and can bring a support person such as a family member, their representative or a support worker. Where appropriate, a participant's representative or support person can provide input to the independent assessment ensuring an accurate picture of functionality is captured.

However, the NDIA also acknowledges there may be exceptional circumstances where it may not be appropriate to request an individual undertake an independent assessment. This includes:

- risk and safety: where the process is likely to do more harm than benefit to the individual, and may pose a safety risk to the individual or assessor, or
- the assessment is inaccessible or invalid, or where there may be concerns about the process of producing valid information, and other sources and/or forms of information are better suited.

7. Developmental needs of children.

Independent assessments will apply to all prospective participants and participants over the age of seven from mid-2021.

The NDIA is currently considering how best to implement independent assessments for children under seven years. Because young children grow and change rapidly, the NDIA is also

Commented [PWDA41]: It is not clear where and how this exception would be made and how.

Commented [PWDA42]: As there is no complaint mechanism available to people with disability around the actual mechanism, it is difficult to see how this would work.

Commented [PWDA43]: The changes proposed in the NDIS Act around early intervention are of concern, especially when taken in consideration with the fact that early intervention is by nature implemented early. Children of any age should not be subjected to these types of assessments by adults, especially children who are likely to experience harmful effects or those who have experienced sexual abuse or trauma.



considering how to best use the independent assessment process to inform the services and supports young children need in their NDIS plan. This consideration will occur within the Early Childhood Early Intervention Implementation Reset Project, which is currently being consulted on nationally.

The NDIA is also undertaking specific consultation to ensure the tools work for everyone over the age of seven years.

8. Independent assessments and NDIS access and planning decisions.

Independent assessors will not make decisions about a person's access to the NDIS or their plan funding. Those decisions will continue to be made by a NDIA delegate. Prospective participants and participants will be able to request a review or appeal decisions made by the NDIA if they feel the decision is wrong.

In this regard, it is important to clarify that the results of the independent assessment are an input into helping the NDIA determine where a person's functional capacity lies on a continuum in relation to the wider Australian population, with regard to the six activity domains in the NDIS Act.

Independent assessments of participants and/or prospective participants will be a key source of information the NDIA delegate will consider in making a decision about a person's eligibility for the NDIS and/or their plan. However, NDIA delegates will continue to, as they always have, consider other matters and information produced by the person with disability, such as environmental factors, the presentation of their condition (i.e. episodic) and whether they were having a typical day for them.

9. NDIS participants and the sustainability of the NDIS.

In the context of public discussion about the introduction of independent assessments, there has been regular reference to the sustainability of the NDIS. Sustainability of the NDIS will always be considered in any decisions made about the NDIS – it is stated in the NDIS Act and it is in all Australian's interests to ensure that the growth of the NDIS is sustainable.

Commented [PWDA44]: Independent assessments themselves will not be able to be appealed and this removes a fundamental principle around being able to make complaints and having recourse to justice. It is not clear who the complaints mechanism or body will be – provisional psychologists, for example, are not covered by Australian Health Practitioner Regulation Agency (Ahpra). Neither is anybody practicing outside of their field of expertise.

Commented [PWDA45]: Given that the assessment is based on both reporting and observation, it is difficult to see how subjective interpretation will adequately capture an understanding of a persons' disability.

Commented [PWDA46]: In 2019, there was a \$4.2 billion underspend of the NDIS. The NDIS has consistently been underspent – the cost of the scheme has, contrary to media reports, never "blown out". Internal constraints have reportedly always been applied in order to restrict or limit funding, including via the use of total reference packages.



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Independent assessments are not an attempt to remove supports for people with permanent and significant disability or to prevent them from accessing the NDIS. Rather the rollout of independent assessments is intended to ensure that the people the NDIS was intended to support are supported to become participants and go on to receive a personalised plan budget which they can then use flexibly, with more choice and control.

Growth of the NDIS is expected to continue as envisaged, supporting around 500,000 by 2023.

Simply put, the implementation of independent assessments will provide equity and consistency in decision making, more closely align funding with individual capacity and need, and enable a greater focus on plan implementation where participants are able to exercise choice and control over the supports they need.

10. Personalised budgets.

From late 2021, information from participant's independent assessment(s) will be used as a key input to determine a participant's personalised plan budget. Using information that is consistently gathered will ensure each participant's personalised budget reflects their functional capacity, including the impact of their environment, such as the informal supports available to the participant and other contextual factors such as locality or circumstance.

This will mean the current approach to creating a participant's budget will change. Currently, a plan budget is made up of individual reasonable and necessary supports. Listing each and every reasonable and necessary support in a person's plan has limited people choosing and changing the supports they buy.

Shifting to more personalised budgets is in keeping with the underpinning objects and principles of the NDIS Act and will enable planning meetings to be more holistic and focussed on how to most effectively use the participant's plan funding to pursue goals and aspirations.



Conclusion:

Independent assessments are not an end in themselves. They are an important way to ensure a more participant-centred planning process greater flexibility, transparency and consistency for participants. They will allow participants to receive a more flexible plan budget to access services they need and help them pursue their goals and aspirations.

Independent assessments will also supplement other reforms which have been developed to improve the way people with disability experience the NDIS . These reforms were set out in an [Information Paper](#) released by Minister Robert on 24 November 2020 and include:

- legislating the NDIS Participant Service Guarantee, which sets timeframes for decisions made by the NDIA and service standards for how the NDIA engages and works alongside people with disability in delivering the NDIS;
- supporting participants to have greater flexibility in spending their plan funding;
- removing the administrative burden felt by participants and providers in organising and managing payment;
- providing more guidance on the boundaries of the NDIS, such as the delineation between the supports provided by mainstream services such as health and education and goods or services that should be paid for using other income; and
- expanding early intervention for young children including through a reset of Early Childhood Early Intervention.

The roadmap for these improvements-informed by participant feedback-was announced by Minister Robert on 28August2020 and is encapsulated in the [NDIS Participant Service Charter](#) and [Service Improvement Plan](#).

DSS and the NDIA acknowledge the rollout of independent assessments and the above reforms represent a significant change for people with disability interacting with the NDIS.

DSS and the NDIA are committed to continuing to consult, discuss and provide more information regarding these changes leading up to roll out later this year.

The number of submissions provided to the NDIA's consultation process, and the interest in the information sessions held by the NDIA demonstrate the shared commitment all Australians have to ensuring the NDIS is set up for the future. DSS and the NDIA welcome the contribution of the entire community in shaping their implementation.

We all have the same aim – to ensure that the people the NDIS was designed for can access the support they need as well as have greater choice and control over their lives – now and into the future.

With the input of participants, families and carers we will reform the NDIS to be a scheme that Australians can trust and rely on now and into the future. One that gives a participant:

- a more empowering, participant-centred planning experience;
- more control over their supports and who delivers them;
- increased transparency over how and why decisions are made;
- a more flexible budget to use as needed;
- clarity about what the NDIS covers; and
- a smooth and easy experience.

Timetable for legislative changes

Following conclusion of the current national consultations on 23 February 2021, there will be a subsequent consultation process on changes to the NDIS Act.

The draft legislation will take into consideration the outcome of the NDIA's consultations and recommendations of the Joint Standing Committee on the NDIS' Final Report on NDIS Planning. It will also reflect, where possible, any issues raised during this current inquiry into independent assessments, noting the Government's intention is to introduce the Bill to Parliament for passage by 1 July 2021.

Notwithstanding the legislation is intended for passage by 1 July 2021 independent assessments will not be used as a basis for planning decisions until late 2021.



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For individual advocacy support contact the **Wayfinder Hub** between 9 am and 5 pm (AEST/AEDT) Monday to Friday via phone (toll free) on **1800 843 929** or via email at info@wayfinderhub.com.au.

Submission contact: Amanda Ellis, Senior Policy Officer: AmandaE@pwd.org.au

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