We stand strong against the NDIA’s independent assessments proposal

PWDA’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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# About this submission

People with Disability Australia (PWDA) welcomes this opportunity to comment on the Joint Standing Committee on the National Disability Insurance Scheme’s (NDIS Joint Standing Committee’s) inquiry into the proposed use of independent assessments.

PWDA’s approach to this submission is to critique the terms of reference of the NDIS Joint Standing Committee’s inquiry into independent assessments, present the views of our members, and highlight comments we have already made to the Australian Government and in the public arena.

We have included a number of additions to our submission. These include:

* a joint sector statement calling for the independent assessments proposal not to proceed as it is currently envisaged (the section What the disability sector wants).
* an Easy Read summary of a PWDA member survey on independent assessments (Addendum A)
* the full results of a survey of members where the majority expressed deep concerns about independent assessments (Addendum B)

PWDA has also prepared a separate critique of the National Disability Insurance Agency’s (NDIA’s) submission to this inquiry and plans to submit this as a supplementary submission by 9 April 2021.

**We oppose the independent assessments proposal like dozens of other organisations**

PWDA is one organisation among many in the disability sector which opposes the NDIA’s independent assessments proposal.

PWDA helped write a sector statement opposing so-called independent assessments, then [released it publicly](https://everyaustraliancounts.com.au/ndis-sector-statement/) 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](https://australianautismalliance.org.au/)

[Australian Federation of Disability Organisations](https://www.afdo.org.au/)

[Children and Young PWDA](https://www.cyda.org.au/)

[Disability Advocacy Network Australia (DANA)](https://www.dana.org.au/)

[Every Australian Counts](https://everyaustraliancounts.com.au/)

[First Peoples Disability Network](https://fpdn.org.au/)

[Inclusion Australia](https://www.inclusionaustralia.org.au/)

[National Ethnic Disability Australia](http://neda.org.au/)

[PWDA](https://pwd.org.au/)

[Women with Disabilities Australia](https://wwda.org.au/)

[Young People in Nursing Homes Alliance](https://www.ypinh.org.au/)

*Plus nine other organisations that initially joined us:*

[Autism Aspergers Advocacy Australia (A4)](https://a4.org.au/)

[Blind Citizens Australia](https://www.bca.org.au/)

[Brain Injury Australia](https://www.braininjuryaustralia.org.au/)

[Deaf Australia](https://deafaustralia.org.au/)

[Deafblind Australia](http://www.deafblind.org.au/)

[Deafness Forum of Australia](https://www.deafnessforum.org.au/)

[Down Syndrome Australia](https://www.downsyndrome.org.au/)

[National Mental Health Consumer and Carer Forum](https://nmhccf.org.au/)

[Physical Disability Australia](https://www.pda.org.au/)

*And at least 92 other people and organisations that subsequently joined our campaign:*

[AED Legal Centre](https://www.aed.org.au/)

[All Means All](https://allmeansall.org.au/)

[Aspergers Victoria](http://www.aspergersvic.org.au/)

[DACCSA Disability Advocacy](https://www.dacssa.org.au/)

[Disability Justice Australia](http://www.justadvocacy.com/)

[Disability Law Queensland](https://dlq.org.au/)

[DRC Advocacy](http://www.drc.org.au/)

[Enhanced Lifestyles](http://www.enhancedlifestyles.com.au/)

[Leadership Plus](http://leadershipplus.com/)

[NOFASD Australia](https://www.nofasd.org.au/)

[People with Disabilities ACT](https://www.pwdact.org.au/)

[People with Disabilities Western Australia](http://pwdwa.org/)

[Polio Australia](https://www.polioaustralia.org.au/)

[Women with Disabilities ACT](https://wwdact.org.au/)

[Women with Disabilities Victoria](http://wdv.org.au/)

[Youth Disability Advocacy Service](https://www.yacvic.org.au/ydas)

[Syndromes Without A Name (SWAN) Australia](https://swanaus.org.au/)

[Queensland Advocacy Incorporated](https://www.qai.org.au/)

[Genetic Support Network of Victoria](http://www.gsnv.org.au/)

[Darwin Community Legal Service](http://www.dcls.org.au/)

[WA’s Individualised Services (WAiS)](https://waindividualisedservices.org.au/)

[Yellow Ladybugs – Autistic Girls and Women](http://www.yellowladybugs.com.au/)

[Project Potential Adelaide](http://www.projectpotential.com.au/)

[Grow Support Services](https://growsupportservices.com.au/)

[Imagine More](https://imaginemore.org.au/)

[IN HOUSE NOUS](https://inhousenous.com.au/)

[Illume Learning](http://www.illumelearning.com.au/)

[Fragile X Association of Australia](http://www.fragilex.org.au/)

[National Disability Services](https://www.nds.org.au/)

[Youth Disability Advocacy Network (YDAN)](https://www.ydan.com.au/)

[Special Voices](http://www.specialvoices.com.au/)

[Rights in Action](http://www.rightsinaction.org/)

[The IndividualiTree](http://www.theindividualitree.com/)

[Queenslanders with Disability Network (QDN)](https://qdn.org.au/)

[Jane Wardlaw Disability Consultant](http://www.janewardlaw.com.au/)

[South West Autism Network (SWAN)](https://www.swanautism.org.au/)

[Different Journeys](https://www.differentjourneysautism.com/)

[Sporting Dreams Queensland](http://www.sportingdreams.org.au/)

[Liberty Disability Services](https://www.libertydisabilityservices.com.au/)

[Accessability WA Inc](http://www.accessability.org.au/)

[Australian Disorders of the Corpus Callosum (AusDoCC)](https://www.ausdocc.org.au/)

[Gifted 2E Support Australia](https://www.gifted2esupport.com.au/)

[Karina and Co](https://www.karinaandco.com.au/)

[Association for Children with Disability](https://www.acd.org.au/)

[Mobile Attendant Care Service (MACS)](https://macsinc.org.au/)

[Independent Advocacy SA](http://www.independentadvocacysa.org.au/)

[Community Resource Unit](http://www.cru.org.au/)

[Child Matters | Teen Matters](https://www.childmatters.com.au/)

Square Peg Support Solutions

[South West Sydney Therapy](http://www.southwestsydneytherapy.com.au/)

[Minerva Allied Health Services](https://www.minervaalliedhealth.com/)

[Avenues Lifestyle Support Association](http://www.avenues.org.au/)

[Mental Health Association of Central Australia](https://mhaca.org.au/)

[Foundation of Hope Therapies](http://foundationofhopetherapies.com/)

[World Access For The Blind – Australia](https://www.worldaccessfortheblindaustralia.org.au/)

[Hub Community Network](http://www.hubdisabilitysupport.org.au/)

[Action For People With Disability](https://www.actionadvocacy.org.au/)

[Regional Disability Advocacy Service (RDAS)](https://rdas.org.au/)

[Allevia](http://www.allevia.org.au/)

[Leisure Options](https://www.leisureoptions.com.au/)

[Rise](https://www.risenetwork.com.au/)

[IDEAS – Information on Disability Education & Awareness Services](http://www.ideas.org.au/)

[Diversity and Disability Alliance](http://www.ddalliance.org.au/)

The Possible Bridge

Pickle Arts Therapy

[MS Australia](https://www.msaustralia.org.au/)

[Carers and Parents Support Group](http://www.facebook.com/Carers-Parents-Support-Group-Inc-1610658229151875)

[Advocacy for Inclusion](https://www.advocacyforinclusion.org/)

[Mission Australia](https://www.missionaustralia.com.au/)

Owen Kessels – Clinical Social Worker, MAASW, AMHSW

[Muscular Dystrophy Queensland](http://mdqld.org.au/)

[Sussex Street Community Law Service](http://www.sscls.asn.au/)

[Equity Works](https://www.equityworks.org/)

[121 Care](http://www.121care.org.au/)

[Out Loud Developmental Services](https://www.outlouddevelopment.com/)

[Rights Information and Advocacy Centre (RIAC)](http://www.riac.org.au/)

[South Burnett CTC](https://sbctc.com.au/)

[Victorian Council of Social Service (VCOSS)](https://vcoss.org.au/)

Coactive Occupational Therapy

[Early Childhood Intervention Australia VIC TAS](http://www.eciavic.org.au/)

[Amazing Ageing Psychology](https://amazingageingpsychology.com.au/)

[ACTS3](https://www.acts3.org.au/)

[Melbourne East Disability Advocacy (MEDA)](https://meda.org.au/)

[Community Disability Alliance Hunter (CDAH)](https://www.cdah.org.au/)

[Kevin Heinze Grow](https://kevinheinzegrow.org.au/)

[Sacred Heart Mission](https://www.sacredheartmission.org/)

[Interchange Loddon Mallee Region](https://www.interchangelm.org.au/)

[Rape & Domestic Violence Services Australia](https://www.rape-dvservices.org.au/)

[Domestic Violence Victoria (DV Vic)](http://www.dvvic.org.au/)

[Domestic Violence Resource Centre Victoria (DVRCV)](http://www.dvrcv.org.au/)

[Kinchela Boys Home Aboriginal Corporation](https://kinchelaboyshome.org.au/)

[Domestic Violence NSW](http://www.dvnsw.org.au/)

**What the disability sector wants**

**The Australian disability sector holds significant concerns about the Federal Government’s planned changes to how people with disability will access the NDIS and, most importantly, how they will receive support.**

Under the planned changes, all future NDIS participants will have to undergo a mandatory assessment in order to access the scheme. Existing participants will progressively be required to undergo the same assessment process before they receive their next NDIS plan and funds.

These assessments will be used by the NDIA to decide who will be given access to the scheme, and how much funding and support they will receive.

These changes will fundamentally alter the individualised and personalised nature of the NDIS. While we all want greater consistency, we are very concerned this increasingly automated process will not adequately consider individual need and circumstance.

This is not the NDIS we fought for.

The NDIS has had a positive impact on many people’s lives. But there is also room for improvement.  The scheme is complex and constantly changing. It is hard to navigate. There are problems with fairness and consistency. While it is working well for some people, others are missing out.

We want to work with the Australian Government and the NDIA to change this picture. We want to deal with problems and come up with solutions that work for participants. We want to make sure this is the world-leading scheme we believe it can and should be.

Unfortunately, we have not seen evidence that what the Government is planning will resolve current problems with the scheme. In contrast these assessments, and the new process for determining individual plans and budgets, may actually compound existing problems or even create new unintended ones.

The introduction of mandatory assessments is the biggest change to the NDIS since it began. Despite the scale and cost of the changes, they have not been rigorously tested or undergone an independent evaluation. Consultation has been rushed and the questions and concerns of people with disability, their families and the organisations that support and represent them have not been addressed.

Based on the information released by the NDIA, we are concerned that a desire to cut costs is the main motivation for the hurried introduction of these reforms.

We want the NDIS to succeed. But we cannot support legislative or operational changes which we believe undermine the intent of the scheme. And may leave people with disability without the support they need.

An NDIS that serves all Australians with disability will be stronger and fairer if it:

* Upholds the rights and respects the dignity of people with disability
* Involves people with disability and their families in all stages of the assessment and decision-making process
* Is free from conflict of interest and bias
* Based on the principles of natural justice including review and appeal.

## ****Our concerns with the planned changes include (but are not limited to):****

### Concerns about the way assessments will be carried out:

* Assessments will be carried out by outsourced private contractors using standardised tools in as little as three hours. Assessors will not be known to the person. As a result, it will be difficult to capture individual complexity or build a comprehensive and accurate picture of people’s needs and circumstances.
* Developing a complete and accurate understanding of the functional abilities of people with “invisible” or complex disabilities requires specialised skills and experience. We are not confident that the planned model takes this into account.
* People with disability from a Culturally or Linguistically Diverse (CALD) background, LGBTIQA people with disability as well as First Nations applicants and participants also require specialised expertise and cultural competence from assessors. Again, we are not confident that the proposed model adequately addresses their needs in a culturally safe way.
* The results of the assessment cannot be challenged or appealed. In fact, people will not be given a copy of the full assessment report unless they apply to see it.
* These assessments are not genuinely independent but performed by an organisation/organisations contracted by the NDIA, creating a conflict of interest.
* Requiring people with disability to work with someone unknown to them will be difficult, even damaging, to those who have a history of trauma, abuse or violence. While a small number of people will be granted an exemption, it is not clear who or how this will occur.
* Once an assessment has started, risks may become clear and trauma may occur. This may not have been obvious when the assessment started. It is not clear if or how support will then be provided.
* The process relies on additional people taking part in the assessment, such as a family member or carer. For some adults with a disability, this is not appropriate. Others may have no-one in their lives who can give accurate, reliable or independent information.
* The proposed use of telehealth facilities to undertake assessments with participants in rural and remote areas may make it difficult for some people with disability to fully participate.

### Concerns with how the assessments will be used to determine participant plans and funding:

* The mandatory assessment will now be the primary tool to determine a person’s NDIS budget. But how the assessment results will be used to do this has not been explained. Nor have the results of any modelling or testing been made publicly available.
* The tools chosen are designed to be used for screening or assessing functional capacity. Using the tools to then determine an appropriate level of support and allocation of funding is however untested and untried. To our knowledge, this would be one of the first times in the world the tools would be used in this way. Before such a radical reform is introduced, we believe there must be strong research and evaluation of the proposed methods. To date, there has been none.
* There will be very few circumstances where the plan and budget can be changed after the assessment is complete. NDIS planning meetings will instead focus on how to spend already allocated funds rather than examining what support people need.
* The proposal to repeat the process at different life stages and at least every five years creates additional stress and anxiety for participants and their families.

### Concerns about the impact of these assessments on the availability of support for participants:

* The assessors who are contracted to do these assessments will not be able to offer other services to NDIS participants. We are concerned this will significantly reduce the number of qualified therapists available to support people with disability and their families – particularly in rural and regional areas.

### We want the scheme to be consistent and fair.

But we also want to make sure that people with disability get the support they need. There are too many unanswered questions and concerns for this proposal to continue in its current form.

# Our recommendations

Following on from our concerns laid out in the section, what the disability sector wants, we ask that the Joint Standing Committee recommend that the Australian government implement the following recommendations:

**Recommendation 1 –** That the Australian Government immediately cease the rollout compulsory assessments as currently planned.

**Recommendation 2 –** That the Australian Government not proceed with the independent assessments proposal designed by the National Disability Insurance Agency and others.

**Recommendation 3 –** That the Australian Government undertake a robust and transparent outcome evaluation of the current pilot of the new assessment process. This evaluation must be independent of the NDIA and be led by people with disability and the representative organisations that support them.

**Recommendation 4 –** That the Australian Government not use independent assessments on people wanting to access the NDIS, or stay on the NDIS.

**Recommendation 5 –** That the Australian Government not proceed with proposed legislation to rewrite the *National Disability Insurance Scheme Act 2013* and its definition of what is reasonable and necessary under the Act.

**Recommendation 6 –** That the Australian Government undertake robust, independent and transparent trials of alternative approaches to improving consistency in access and planning – such as allowing a person’s existing health professionals to complete assessments using the same tools.

**Recommendation 7 –** That once the trials and evaluations are complete, the Australian Government engage in a meaningful co-design process with people with disability and their representative organisations that support them, to ensure a fair and consistent approach to both access to the scheme and planning and to ensure people with disability receive the support they need.

**Recommendation 7 –** That the Australian Government create a bulk bill Medicare item, where people with disability in need of evidence for access and planning purposes in the scheme, can have the trusted professionals they choose bulk bill for the required evidence.

# Our response to the Terms of Reference

PWDA acknowledges the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) adopted Terms of Reference for its inquiry into independent assessments.

While PWDA understands these Terms of Reference are not changeable, we highlight that if we were consulted on the terms, we would have pushed for a broader inquiry that assessed whether independent assessments should be introduced at all.

We would have preferred term of reference *j* appeared as *a* on the list and read:

As part of the committee’s role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will inquire into and report on independent assessments, with particular reference to: … j. the appropriateness of independent assessments as a policy of government for the National Disability Insurance Scheme operated by the federal government on behalf of people with disability, National Cabinet, and the states and territories. ~~for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds~~.

That said, PWDA notes selection criteria *l* is very broad and could encompass answering a question about the appropriateness of independent assessments *at all,* in its wording:

l. any other related matters

PWDA recommends the Joint Standing Committee on the NDIS uses term of reference *l*
to answer a shortened and therefore broader version of question *j* that contains our *core advice to government:*

* that the independent assessments proposal designed by the government not proceed
* that independent assessments are not used on people wanting to access the NDIS, or stay on the NDIS ~~without people’s informed consent~~
* that proposed legislation to rewrite the *National Disability Insurance Scheme Act* 2013 and its definition of what is reasonable and necessary under the Act*,* not proceed.

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

PWDA does not believe any development work, modelling, or reasons or justifications warrant the introduction of the independent assessments proposal put forward by the NDIA last year without meaningful consultation with people with disability.

PWDA does not agree that the so-called independent assessments proposed by the NDIA for the NDIS are the same kind of functional assessments recommended by Mr David Tune AO PSM in the [*2019 review of the NDIS Act and the new NDIS Participant Service Guarantee*](https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-insurance-scheme/ndis-legislative-reforms)**.**

We think the NDIA, and the now former Minister for the NDIS, the Hon Stuart Robert MP, were mistaken when they claimed their model of independent assessments were what Tune asked for in his review recommendations.

While we acknowledge recent revelations about extra material being inserted into Tune’s materials by government parties, PWDA still believes it would be misleading or deceptive for any Australian Government representative or their contractors to claim the NDIA’s proposed assessments are what Tune asked for in his recommendations.

Our organisation notes the CEO of Centre for Digital Business Marie Johnson’s detailed feedback on modelling and ethical research methods, and true trauma-informed design and development, which she outlined in her published Independent Assessments Submission 33**.**

We encourage you listen to Ms Johnson as a person with deep knowledge of the NDIA and its systems. She is a mother and grandmother of people with disability who has bravely highlighted what are extensive flaws in the approach to so-called independent assessments for the NDIS.

We surveyed our members about the independent assessments proposal last year and they held deep concerns we will outline later and have flagged in our survey report (see the Addendum A Easy Read summary and the Addendum B full survey report).

## The impact of similar policies in other jurisdictions and in the provisions of other government services

Now that the NDIA has named the contractors it intends to commission to conduct its
so-called independent assessments, it seems abundantly clear these assessments are unlikely to be independent.

PWDA expect the so-called independent assessments conducted by contractors may have similar, damaging effects as those used in other jurisdictions, such as the Northern Territory and the United Kingdom, and for other schemes, such as Workcover. We believe this is a significant risk if the NDIS Act is changed as forecast in proposed legislation leaked to the public by Shadow Minister for the NDIS, the Hon Bill Shorten MP.

PWDA conducted a survey of its members and many had encountered similar assessments to those proposed, when they were assessed by Workcover representatives and for Centrelink’s Disability Support Pension. These members were extremely concerned they would suffer similarly traumatic, discriminatory experiences if independent assessments were introduced for people wanting to access the NDIS and people wanting to stay on the NDIS as participants.

Some of our members had become suicidal after their treatment under similar assessments to those proposed by the NDIS. Some were suicidal at the thought of the NDIS’s specific model for independent assessments. Many people in our survey expected to have harrowing experiences under the NDIA’s proposed model.

We point you to the pages and pages of their feedback contained in Addendum B.

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

Given the NDIA’s rushed tendering process to appoint contractors to undertake independent assessments – before the Australian Government’s retrospective consultation processes had even concluded – we think it’s obvious the NDIA has already determined how much human and financial resources it would like to dedicate to independent assessments.

We think the independent assessments proposal is flawed and no monetary figure will make it a fair, un-traumatic, valid way of assessing people.

In fact, we would like to highlight that by spending this money to implement the NDIA’s proposed unfair, exclusionary system which will likely exclude people with disability or dramatically reduce their personal budgets, the assessments will take monetary support away from people with disability, making it harder for the agency to effectively implement the NDIS on behalf of the states and territories and the federal government.

## The independence, qualifications, training, expertise and quality assurance of assessors

The job ads already run by contractors to the NDIA for people to conduct the NDIA’s
so-called independent assessments make it clear that assessors will have minimal experience, qualifications, training and expertise.

PWDA expect the roles will become a job often performed by relatively new practitioners with limited professional experience.

PWDA is concerned assessors will not be independent. We note reports that at least one parent company with a commercial interest in the NDIS has advertised assessor jobs on behalf of its subsidiary company which has been appointed by the NDIA to conduct assessments.

We believe assessors working for such an organisation could operate with an active conflict of interest, where they give the NDIA want it wants – applicant knock-backs and dramatically insufficient or reduced proposed plan budgets – in exchange for preferred provider status.

PWDA is also concerned assessors may have compromised or highly compromised quality assurance standards or poor commitment to accuracy and fairness.

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

PWDA is extremely concerned about the potentially flawed and unethical use of unproven adaptations of standardised functional assessment tools, particularly for deciding on plan budgets.

PWDA is also concerned about the potential use of artificial intelligence tools without human discretion and intervention being a vital part of decision-making.

We are also concerned our data will be added to large government datasets and then used for research not conducted using ethical practice.

PWDA thinks the proposed tools and their proposed uses are inappropriate.

## The implications of independent assessments for access to and eligibility for the NDIS

PWDA is concerned so-called independent assessments will replace other validly conducted assessments from treating professionals who know a person with disability and are aware of their functional limitations, goals for the future, and extended medical history.

PWDA is concerned people’s access to the scheme will be reduced and less people will become or remain eligible, due to inadequate or negligent assessment.

We are also concerned that decisions will be made by unsuitably qualified, junior people who are untrained in a person’s disability. We are concerned people making decisions will not be covered by their professional organisations in their decisions and therefore will not take into account proper ethical frameworks.

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

PWDA expects that the use of so-called independent assessments will have dramatic implications for NDIS planning as they seek to fund a cookie-cutter definition of what is reasonable and necessary by disability type, rather than its historical and purposefully broad definition of what is reasonable and necessary for a particular person to meet their individual needs and goals.

PWDA expects that if the NDIA is successful in getting its proposed changes to the *National Disability Insurance Scheme Act* 2013 across the line, people will struggle and be unable to have their reasonable and necessary individual needs and goals supported.

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

PWDA acknowledges the NDIA intends that there be some circumstances where people are identified as people unsuited to assessments.

PWDA is concerned that many people who will suffer harm from assessments will still undergo them, and many more people than those who self-identify as unsuitable and successfully opt out of the assessment will be assessed.

We are concerned that people will be unethically assessed and unethically be researched as part of the so-called independent assessments regime. We are concerned the data collected will be retained and used against them for future purposes.

## Opportunities to review or challenge the outcomes of independent assessments

PWDA is concerned people will have limited options for contesting so-called independent assessments.

PWDA believes it is inappropriate that full assessments will not be shared with people by default. We are also concerned redacted or incomplete full assessment reports will be shared when ones are requested.

We believe fair and just decisions will not be made in the absence of an appeals convenor avenue of appeal.

## The appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds

PWDA understands the NDIA does not believe all the tools that will be used in the execution of so-called independent assessments will be culturally safe for key population groups, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds.

PWDA does not believe so-called independent assessments will be culturally safe for people with disability.

## The appropriateness of independent assessments for people with particular disability types, including psychosocial disability; and

PWDA is concerned about the use of so-called independent assessments for people with particularly disability types such people with intellectual and cognitive disability.

Additionally, we are concerned about the use of so-called independent assessments for people with diagnosed and undiagnosed psychosocial disability, including Post-Traumatic Stress Disorder and Complex Post-Traumatic Stress Disorder.

For people with a diagnosed psychosocial disability, the so-called independent assessments are not able to capture the permanence of psychosocial disability, particularly noting the episodic nature of some forms of psychosocial disability.

For people with undiagnosed psychosocial disability, the so-called independent assessments are not able to support pathways toward an appropriate diagnosis or diagnoses. Diagnosing psychosocial disability is complex, can take considerable time, and requires significant rapport and professional experience from trusted professionals. Therefore the skills of so-called independent assessors, and the proposed model of so-called independent assessments are inappropriate.

## Any other related matters

As we stated earlier, we believe that the NDIS Joint Standing Committee should use this term of reference to recommend our core advice to Government:

l. any other related matters

PWDA recommends the Joint Standing Committee on the NDIS uses term of reference *l*
to answer a shortened and therefore broader version of question *j,* that contains our *core advice to Government:*

* that the independent assessments proposal designed by the government not proceed
* that independent assessments are not used on people wanting to access the NDIS, or stay on the NDIS
* that proposed legislation to rewrite the *National Disability Insurance Scheme Act* 2013 and its definition of what is reasonable and necessary under the Act*,* not proceed.

# What our members say about NDIS assessments

PWDA has surveyed its members on the Australian Government’s plans to introduce independent assessments for the NDIS.

The survey of PWDA members, conducted in October and November 2020, revealed high levels of anxiety from the disability community about the proposed functional assessments.

People with disability are concerned they will be the subject of additional trauma from independent assessments, with many highlighting they have been the subject of trauma in the past. Independent assessments bring on feelings of anxiety, with our survey finding:

* + 74% of the people we surveyed thought independent assessments were a bad or extremely bad idea
	+ we expect this figure to be much higher in future surveys, given people are now more familiar with the NDIA’s plan to roll out NDIS assessments
	+ the majority of people we surveyed felt unexcited, unhappy, anxious, defeated and overwhelmed at the government’s plans to start independent assessments
	+ some people felt suicidal about the idea of the assessments
	+ 47.9%, had previously undergone an independent assessment as part of a scheme, so were concerned based on their understanding of what assessments are like
	+ 25.5%, said the Australian Government should not go ahead with independent assessments for the NDIS.

Our members wanted the Australian Government to tell them specific things about independent assessments. Key things included:

* + Where is the choice and control promised with the NDIS?
	+ What exactly is involved and why it is necessary to have it?
	+ Will your process continue the NDIS’ confusion in understanding the difference between diagnosis, impairment and disability – in contradiction of the NDIS Act.
	+ Who will do the assessments and what incentives will they have to reject people?
	+ What qualifications will people have? Members are concerned people will be assessed by someone unexperienced with their disability or unqualified to judge their functional impairment.
	+ Will suitably qualified people who become assessors end up being unable to continue being treating practitioners?

People wanted transparency and to be consulted in a reform that has many people worried. Many did not want the plans to progress.

## Executive summary

Our member survey was launched on 30 October 2020 and closed on 13 November 2020.

The survey was promoted via email to PWDA members only. For that reason, this survey is best considered as an internal survey of PWDA’s membership.

PWDA’s membership is made up of people with disability with all types of disability and reflects the diversity of our disability community.

We received a total of one hundred and forty-six (146) responses to the online survey. The questions in our survey were as follows:

* + Question 1: Do you think NDIS independent assessments are a good idea?
	+ Question 2: How are the government’s plans to start independent assessments making you feel?
	+ Question 3: Have you had an independent assessment?
	+ Question 4: Are you planning to take part in the second pilot of independent assessments?
	+ Question 5: Have you undergone an independent assessment in any other scheme?
	+ Question 6: What would you like the government to do about independent assessments?
	+ Question 7: Would you like more information from the government about independent assessments?
	+ Question 8: Do you have any other comments about independent assessments?
	+ Question 9: What are your demographics?
	+ Question 10: Is there anything else you want to tell us about your experiences with the NDIS?

A demographic breakdown of people who responded to our survey is as follows:

* + 58.5% of respondents identified as being female, 30.3% identified as being male and 6.3% identified as being non-binary or gender diverse
	+ people aged 51-to-60 (31%) and 41–50 (17.2%) responded at higher rates than people in other age groups
	+ people residing in Queensland (24.1%) and Victoria (22.1%) responded at higher rates than people living in other states and territories
	+ 70.3% of respondents were existing NDIS participants while 18.9% were planning to apply for the scheme in the near future, meaning 88.9% of people who responded to our survey could be affected by independent assessments in the next year
	+ of those respondents who were already participants of the NDIS, 26.5% had undergone three plan reviews, while 18.6% had only had their plan reviewed once
	+ 47.9% of respondents had already gone through independent assessments as part of other schemes or programs.

The key findings from our survey are summarised as follows:

* + 72.6% of respondents said they felt anxious about independent assessments, while 63.2% said they felt defeated and 66.9% said they felt overwhelmed
	+ 74% of respondents thought independent assessments were either a bad or extremely bad idea
	+ 79.4% of respondents were unhappy with the government’s plans to introduce independent assessments
	+ 25.5% of respondents said the federal government should not go ahead with independent assessments
	+ 46.2% of respondents argued people with disability should be able to choose whether they use an independent assessor or their own health professional
	+ 13.8% of respondents planned to take part in the latest trial of independent assessments and 80% of these people were willing to tell us what they thought in the future.

Our members were very clear about what they wanted the Australian Government to do with its plans to introduce independent assessments. Responses to the open-ended questions included in our survey indicated that:

* + people with disability want to exercise choice in how information is gathered to determine eligibility for the NDIS and the supports that should be funded in plans
	+ many people with disability are either opposed to independent assessments or think they should be voluntary
	+ many people with disability have already experienced trauma as a result of participating in similar assessment processes and are opposed to the potential trauma, exclusion and discrimination that independent assessments could introduce to what is an already under-utilised scheme
	+ the majority of people with disability surveyed felt the government should delay its plans to introduce the independent assessments proposal until a way forward can be better determined.

# Addendum A – An Easy Read summary of PWDA’s independent assessments survey

# Addendum B – PWDA’s full independent assessments survey report

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**.**

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