



PEOPLE WITH DISABILITY
AUSTRALIA

Raw Data, Real Insights

**Voices and views of
people with disability on
the Australian Government's
plans for rapid rollout of
NDIS independent assessments**

**A voice
of our
own**

I 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.

People with Disability Australia 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 also a founding member of Disabled People's Organisations Australia (DPO Australia) joining 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.

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I Preface

“Learn what participation means! It’s a two-way street. You [the government] are not listening or including us in our own scheme.”

The principle of “Nothing about us without us” has been at the heart of the disability rights movement for more than 40 years. It stems from an understanding that we are active stakeholders in all matters that affect us.¹

Australia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities. As such, the government has made a legal commitment to uphold the principles that are set out in the Convention. This includes the need to closely consult with and actively involve people with disability when making decisions that may affect us.²

On 28 August 2020, the Minister for the NDIS, Stuart Robert MP announced that the Australian Government would move to roll out compulsory independent assessments for the NDIS from 1 January 2021.³ This unexpected announcement was met with shock, anger and apprehension from many people with disability across the country.

We soon found out that:

- independent assessments were not just being proposed for new people applying for the NDIS. Existing scheme participants would also be subjected to independent assessments as part of the plan review process
- Independent assessments would take between one and four hours to complete which may not be enough time to understand the person with disability and their support needs
- independent assessments would be conducted by a panel of private providers, including occupational therapists, physiotherapists, speech pathologists and psychologists. They could not be completed by a professional who was known to the person with disability.⁴

Last year, Australia was criticised by the Committee on the Rights of Persons with Disabilities for being too heavily reliant on the medical model of disability to determine eligibility for the NDIS. In its concluding observations on the combined second and third reports of Australia, the Committee recommended that Australia review the assessment criteria for the NDIS to ensure it aligned with the human rights model of disability.⁵ The government’s intention to subject potential and existing scheme participants to compulsory medical assessments seemed at odds with this recommendation. The government’s model for independent assessments was also inconsistent with the voluntary, NDIA-conducted functional assessments that were proposed in the 2019 Tune review of the NDIS Act.⁶

¹ The phrase was adopted by Disabled Peoples’ International (DPI) when it was founded in 1981.

² See information available on the Attorney-General’s website here: <https://www.ag.gov.au/rights-and-protections/human-rights-and-anti-discrimination/human-rights-scrutiny/public-sector-guidance-sheets/rights-people-disability>

³ See the Minister’s media release: <https://www.ndis.gov.au/news/5207-landmark-reforms-deliver-promise-australias-ndis>

⁴ See PWDA’s blog released soon after the announcement <https://pwd.org.au/we-are-concerned-about-independent-assessments-for-the-ndis>

⁵ See the Committee’s concluding comments on the combined second and third periodic reports of Australia here: <http://www.t.ly/PwTO>

⁶ See PWDA’s blog released soon after the announcement <https://pwd.org.au/we-are-concerned-about-independent-assessments-for-the-ndis>

See information on independent assessments available at: <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-pilot>

While we were still reeling from the impacts of the COVID-19 pandemic that had so adversely impacted on us, it seemed that the government had been working behind the scenes to radically alter the way that the NDIS would work.⁷ The government was forging ahead with its plans to introduce independent assessments despite the fact that:

- the evaluation report from the first functional assessment pilot, conducted between November 2018 and April 2019, had still not been released to the public.
- the second functional assessment pilot had been put on hold in March 2020 due to the COVID-19 pandemic and as such, has still not been completed.⁸
- people with disability and their representative organisations had not been adequately consulted about the extent and scope of the proposed changes.

The fact that all of this work had taken place, without the direct involvement of people with disability, goes against Australia's obligation to consult with and actively involve people with disability in all matters that affect us.

We remind the government that the NDIS is our scheme. We fought hard to have it established and we are directly impacted by the interactions we have with the scheme every single day. This means we are the experts and as such, our voices should always be at the centre of any proposed changes to the infrastructure of the scheme.

In early September, the National Disability Insurance Agency (NDIA) convened a meeting with disability organisations. This included People with Disability Australia and a number of other disability representative organisations. The purpose of the meeting was to brief us on the government's plans for the introduction of independent assessments. Together, we asked multiple questions on behalf of people with disability, including:

- What was informing the rapid and rash rollout of independent assessments?
- Was this about cost-cutting, or containing the growth of costs in the scheme?
- Why wouldn't it be possible for us to choose our own practitioner to help us make an access request for the NDIS?
- How would independent assessment tools work for the full range of people with disability who may be eligible for the scheme?
- How would independent assessments work for those of us from minority and marginalised population groups?
- Would independent assessments be culturally appropriate for Aboriginal and Torres Strait Islander people and people from Culturally and Linguistically Diverse communities?
- Would independent assessments really improve access and outcomes for those of us living in rural and remote communities?

Following this meeting, PWDA, together with other Disabled People's Organisations and Disability Representative Organisations wrote a joint letter to the Minister for the NDIS to express our concerns. In summary, we asked for the Australian Government to:

1. Immediately stop the planned timeline for the rollout of independent assessments

⁷ See the recently released report from the Disability Royal Commission which highlights the extensive adverse impacts of the COVID-19 pandemic on people with disability available at <https://disability.royalcommission.gov.au/publications/report-public-hearing-5-experiences-people-disability-during-ongoing-covid-19-pandemic>

⁸ See information on independent assessments available at: <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-pilot>

2. Stop mandated independent assessments for existing NDIS participants now and in the future
3. Go back to square one with the planned implementation of independent assessments including:
 - a. Co-design of the independent assessment process for access / eligibility testing with people with disability and their representative organisations
 - b. Further develop the evidence for the use of independent assessments for entry into the scheme and trial this with population groups who face particular barriers to entering the scheme (e.g. First Nations people, people from culturally and linguistically diverse backgrounds, people from low socio-economic backgrounds and people with complex support needs).

Because the idea of independent assessments represented a wholesale change to the way the NDIS would work, we launched a survey to hear what our members had to say about independent assessments. The survey opened on 30 October 2020 and closed on 13 November 2020. We received one hundred and forty-six (146) responses in total.

As you will read in this report, our members poured out their hearts and shared detailed views on what independent assessments meant to them.

Members had a lot to say, so we have made the courageous decision to publish the data in full. We believe people should be able to speak up with their own voices and be heard. It is with this in mind that we have published this report to share our member's concerns about the government's plans for independent assessments.

In late November, we were relieved to find the Australian Government announced that it will be delaying the implementation of independent assessments to mid-2021 pending further consultation. And it released a series of consultation papers to get feedback on the implementation of the scheme.

This delay in implementation and further consultation is a welcome step in the right direction. It means our voices and concerns are being heard. We will be continuing to contribute to these consultation processes.

However, our survey provides compelling evidence that the Australian Government should hit the pause button and undertake further consultation with people with disability to determine whether independent assessments are the right solution for the NDIS.

Australia has something to be proud of in the NDIS. We encourage the government to focus its reforms on making it better and ensuring that it meets its primary goal of improving the lives of people with disability with significant and permanent disability.

Based on feedback provided through our member survey, PWDA will continue to:

- advocate to government for a halt to the rollout of independent assessments.
- promote the need for full and effective consultation and co-design with people with disability.
- promote the principles of "Nothing about us without us".
- advocate for a fair, equitable NDIS that can transform the lives of people with disability.

We thank our members for sharing their views and stories through our member survey. Speaking up takes courage and can stir up strong feelings. Thank you for hanging in there with us. We value your voice and what you have to say.

To the people who said they felt suicidal at the thought of the government introducing independent assessments: We were sorry to learn of your distress. We have reached out to you and we thank you for your bravery in speaking up. If you do need support, please contact:

- Lifeline (24/7) on 13 11 14.
- Suicide Callback Services (24/7) on 1300 659 467.
- Mensline (24/7) on 1300 789 978.

To the people who had some robust feedback for PWDA on the survey design and our advocacy: We acknowledge your comments and will take up your concerns through our policy work and commitment to continuous improvement.

To the government: Please prioritise our voices and what we have to say. The raw data contained within this report provides a real insight into the way people with disability view the government's plans for independent assessments. We believe it is incumbent on government, policy-makers and decision-makers to read all the comments, and take in all our members voices and views in full.

Final note: There are 4.4 million people with disability in Australia, which means we represent 19% of the Australian population. The NDIS plays a fundamental role in providing lifetime care and support to 10% of us with permanent and significant disability. Nothing contained within this survey report takes away from the need for real and systemic change for all people with disability — including the 90% of us who are excluded from the NDIS. As such, we continue to call for a new National Disability Strategy that invests in improving the lives of all people with disability in line with the obligations set out under the Convention on the Rights of Persons with Disabilities.⁹

⁹ See PWDA's submission *A Rights Direction: Delivering on Australia's obligations under the CRPD through the National Disability Strategy 2020–2030* to the second consultation on the National Disability Strategy 2020 and Beyond <https://pwd.org.au/pwdas-submission-in-response-to-the-national-disability-strategy-position-paper-stage-2-consultations/>

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. PWDA is a cross-disability peak organisation and our membership 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. A further 18.9% of respondents said they were planning to apply for the scheme in the near future. This means that 88.9% of people who responded to our survey could be impacted by independent assessments if they are introduced 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 that 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 express opposition 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 that the Government should delay its plans to introduce independent assessments until the model for rolling them out can be better refined.

Question 1 — Do you think NDIS independent assessments are a good idea?

People with Disability Australia asked its members **Do you think NDIS independent assessments are a good idea?**

A huge 74% of the people we surveyed thought independent assessments were a bad or extremely bad idea.

One hundred and forty-six people completed PWDA's survey and ranked their views on a scale of 1 to 5. The start of the scale, 1, was chosen by a small minority of people who thought independent assessments for the National Disability Insurance Scheme were an excellent idea. People choosing the second option, 2, called them a good idea, while 3 was the option for people who were neutral on the idea of independent assessments. The other end of the scale was more popular with our surveyed members. People choosing option 4 described independent assessments as a bad idea, while people picking option 5 believed they were an extremely bad idea.

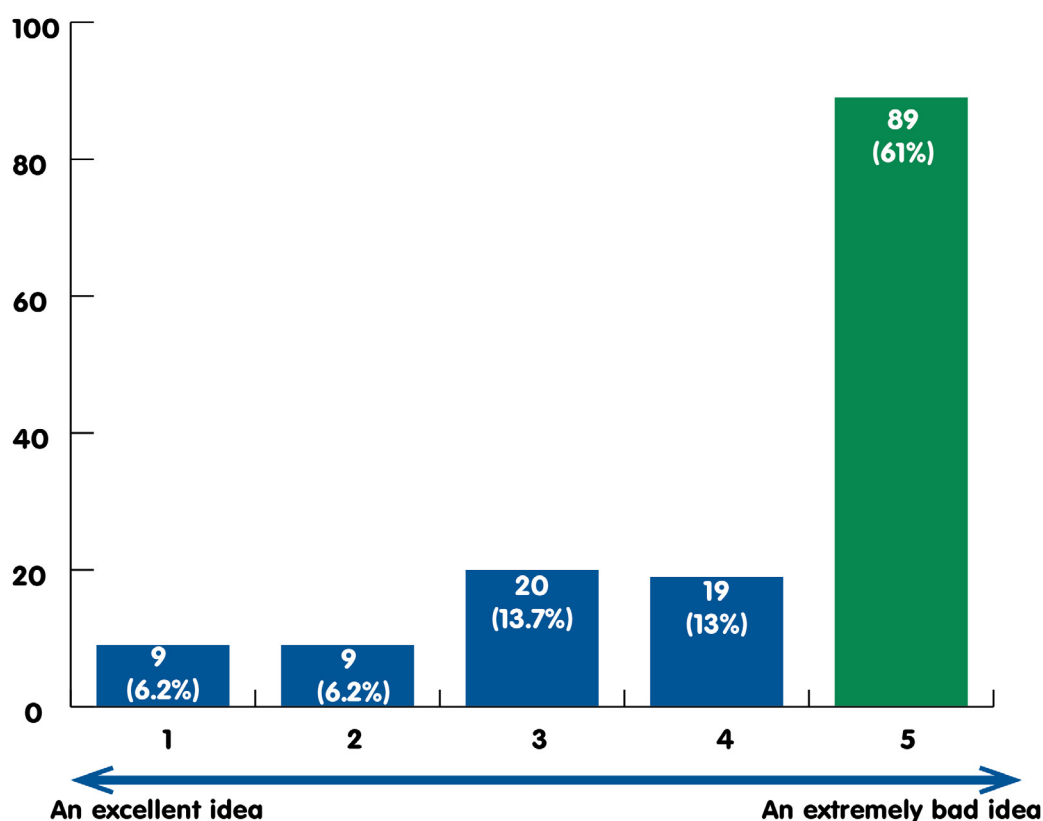


Figure 1 — A green column in a chart shows a 61% majority of people in PWDA's survey thought independent assessments were an extremely bad idea.

All 146 people who took part in the survey answered this question.

The mean or average response to this question was 4 — meaning most people thought independent assessments were a bad idea.

The mode or typical response to this question was 5 — 61% or 89 people thought they were an extremely bad idea. Another 13%, or 19 people, thought they were a bad idea.

A huge 74% of the people we surveyed thought independent assessments were a bad or extremely bad idea.

Some 13.7%, or 20 people, were on the fence while another 6.2%, or nine people, thought independent assessments were a good idea, and another 6.2% or nine people thought they were an excellent idea.

People were extremely vocal about their views on why they thought independent assessments were a good or bad idea. One hundred and thirty-four people shared their views. Here is what they had to say.

■ Why 61% say independent assessments are an extremely bad idea

1. Further interrogation. As a person with a lifelong disability, I'm tired of having to prove I'm still disabled. The health professionals that would be running these assessments are not experienced enough to assess.
2. Disabilities are so varied, I believe it's impossible to fairly standardise these assessments.
3. Independent assessors simply cannot have sufficient context about an individual's disability or circumstances to make informed recommendations from a single meeting.
4. Preparing for NDIS Access took me eight months, and involved assessments and support letters from a multidisciplinary team of doctors and allied healthcare professionals (four of the latter). I needed this because I have multiple complex disabilities and my functioning fluctuates over time. Plus my disabilities are invisible, I am very good at "masking" — appearing neurotypical — and my autism means that I don't express/show my distress like non-autistic people (I appear calm and coping well when I'm not). Having a single professional do this in one session would not have captured the full range of my difficulties or functioning. I would like the NDIA to pay for Access Assessments. It's very expensive. Having functional assessments post-Access should not lead to participants being removed from the scheme. This threat is stressful. Plus it's illogical — by definition you can only get on the scheme if your disability is permanent. So once in, it should be a lifetime membership, even if some years you don't need much support. I would like the NDIA to pay for Access Assessments. It's very expensive. Having functional assessments post-Access should not lead to participants being removed from the scheme. This threat is stressful. Plus it's illogical — by definition you can only get on the scheme if your disability is permanent. So once in, it should be a lifetime membership, even if some years you don't need much support.
5. They take longer to do, you have to pay extra money and they will probably not take report from our service providers.
6. Independent assessors don't know you and might not understand your disability which can lead to misunderstandings, incorrect recommendations, insufficient funding, unnecessary reviews and stress and upset for the participant.
7. My GP, specialist and allied health professionals have far more knowledge about my abilities and needs than can be determined from one visit from a stranger. This whole idea

is just plain dumb. Like many disabled people I have good and bad days, if assessed on a 'good' day it will mean I'll be left unsupported on the 'bad' ones.

8. While the NDIA should be providing funding for reports it requests (directly or indirectly) at access stage in particular — the part of the Tune Report this is supposed to be remedying — this solution is made in bad faith and restricts the rights of people with a disability to choose their healthcare providers. If organisations have to compete for tender for the contract funded by the NDIA, it also represents a massive conflict of interest that may result in reports skewed in favour of money-saving for the NDIS and against the participant/prospective participant. It is also a waste of time and money and expertise, to make people with disability engage with new Allied Health professionals when in many cases they are likely to have more informed, nuanced, and pre-existing relationships with health/therapy professionals of their own. It echoes the failed DSP system and is a blatant restriction of the choice and control for persons with disability that the NDIS is meant to promote. They should be funding these reports, with the choice going to whichever provider the participant/prospective participant chooses. This could be made available as a Medicare item, for instance, or by making funds available directly to the participant with a report-back structure. It is a lazy and potentially very biased response to an urgent shortfall of the NDIS, whose pilot details and consultation process with participants has not been made appropriately public.
9. The very thought triggers iatrogenic trauma. I have a little known & understood genetic disorder that has a massive impact on my life. However, by observing me for a short time you can't necessarily tell how much pain I'm in, how I'll crash when I get home and may not even be able to talk for the next day or two from fatigue... etc. I have been dismissed and ignored by doctors many times. I have been cut open without effective anaesthetic because doctors didn't listen, told that my disability is all in my head... I could go on. I have CPTSD from these experiences. I DO NOT choose to be mostly bedridden. I DO NOT choose to be unable to care for my child. The idea that someone who doesn't know me or my condition, who only sees me for a few hours, could take away the supports I NEED, that those who know me and my condition can attest to my needing... is TERRIFYING.
10. This goes back to the "we don't believe you" type of thinking. Your specialist and other supports know what is going on and don't need to be double guessed. Constant worrying about whether someone can accurately understand your individual circumstance in limited exposure to you is one more anxiety-producing event being imposed on us. When you have a degenerative disease and things are only going to get worse you don't need the extra baggage of having to explain to a stranger over and over again how you feel.
11. The relationship is what makes or breaks communication and information provision. If this is new, short or potentially powerful this does not provide accurate information.
12. Because it will make it harder to get the supports in place that you need because those who don't have an intimate experience of what it's like don't have the understanding of what is needed and will just (say) it's not needed, for example things like physio is needed to keep me on my feet and able to participate in life.
13. I have multiple disabilities and chronic health conditions. It has taken a long time to curate a medical team who understand me and who work with me in the way I need. My conditions all fluctuate and this cannot be judged appropriately with one observation session. I am fearful of strangers making decisions about my livelihood without understanding my history and personal challenges.

14. — short assessment time (20 minutes???)
- based on capability rather than the reality of -dis-ability and impairment which is the main reason why people need NDIS supports
 - there is a dignity issue here as well
 - assessments made by people unfamiliar with our lives, issues, needs, impairments, concerns is a recipe for losing much needed supports
 - an ‘independent assessor’ simply does not have the appropriate knowledge and background understanding of our personal unique experience of disability and the impact of our disability on our lives
 - assessments must include recommendations about support needs and a strong focus on our support needs
 - copies of the Assessment Reports are not being shared with Participants or Prospective Participants and results or outcomes are not being discussed with Participants or Prospective Participants. We need to be involved in every step of any assessment about our lives, with full engagement ensure any report about our lives reflects our true situation. This cannot be carried separately to our lived experience.
 - we also need time to read, understand and potentially dispute any assessment like this that will seriously impact our lives and wellbeing
 - this ‘independent assessment’ process is creating an extra systemic barrier, amongst all the other systemic barriers we face as people with disability
 - it’s a really bad idea because of accuracy issues (the reports written by people who are not involved in our lives, do not know us, and are removed from our lived experience will be flawed assessments), transparency issues (keeping the report from us and not discussing what will be in the report) and policy issues (social model of disability).
15. It is an insult. Yes, sure, we all hear of bullies who identify as having a more severe level of impairment and young people may not need quite as much assistance as they move into adulthood. But once a culture of periodic reviews has been established, it will only take small policy adjustments over time before there are whole groups of people whose impairments are reclassified as health issues rather than disabilities. People with long-term impairments should not have to go through the indignity of continuously needing prove our disabilities.
16. It reeks of the assessments that are used in the UK purely to minimise the amount of assistance people can receive.
17. For complex clients there is no way a 1–4 hour assessment should make life-changing decisions when there is far better evidence available on complex patients from multiple professionals some of which would have seen the patient during regularly and would have professional expertise a fly-in, fly-out assessor would never have. Furthermore it looks like the questions are aimed at stable disability not fluctuating disability that is permanent in nature. A good example is severe refractory epilepsy that has a profound effect on function and manifests itself in the need for high-level life-long care need. A 1–4 hr assessment based on the questions we have seen have not been designed for this type of complex whole-of-body disability.

18. They won't understand mild symptoms I feel. I've been to numerous professionals and not many get it.

19. This is a letter that I wrote recently explaining my concerns

To the Hon Stuart Robert MP,

I have some major concerns (as do a lot of other people) in regards to the proposal to have NDIS independent assessors. I believe that this did not get trialled enough to a variance of disabilities (due to closing the trial early because of the pandemic) and not only that but there was not enough feedback received from participants. You cannot implement someone as big as this without serious consideration and I don't believe that this has occurred.

Relationships are built with the allied health professionals we see, they know our disabilities because we have been seeing them regularly and they understand our needs, almost as good as we do ourselves. How is an independent assessor going to "know" our needs from one brief visit?

I worry what this will do to people's mental health and especially for those that already have mental health issues...the suicide rates are going to sky rocket and I believe those that push this out will be the ones to wear this. There is no duty of care in this decision at all.

I would like you to reconsider this decision, this is not a holistic approach and is going to have the appearance of WorkCover assessors and we know how much that has affected people (my husband for one has been on WorkCover for the past 2 years), my husband doesn't have a mental health condition but he certainly feels the brunt of seeing an independent assessor and I can tell you this is a traumatising experience so I can only just imagine the affect this will have on people that are autistic (like myself), have psychosocial disabilities or co-morbid mental health conditions along with their primary disability.

Please I beg of you to reconsider this proposal and listen to the very people that this will affect and show us that you are actually listening to us.

Kind regards

20. How can somebody diagnose you in that time compared to specialists that have been treating you for years?

21. I've had an ongoing relationship with a speciality organisation that responds to my disability since 1987. That is 33 years. A person who has never met me cannot quickly grasp how, when, where, why my disability impacts me on a daily basis. I have another speciality organisation that responds to a secondary disability that interacts and impacts my primary disability. I've experienced ignorance from NDIS LAC and NDIA lack of experience and drawing incorrect conclusions and that has had a negative impact. No more please.

22. They're insulting to us. How is someone who meets us once going to know better than our testing specialists/doctors who know our in-depth history and needs? It's appalling to hinge everything on a one-off assessment by a random person.

23. People who have complex needs and work with the existing Therapist have a much better understanding than an outsider. In my case I may be a paraplegic but that doesn't determine what I'm physically able due to the extreme over-use injuries in my upper body does. It takes years to a decade for physiotherapist support workers and occupational therapists till you learn what kind of equipment actuations in my daily ability is fitting for a new appointment etc required for my own complex case. It isn't something that is humanly possible for an individual assessor to work out over the course of a few hours. It's not only led to reviews and appeals which would cost the government for money and stress for the

participant. This is being presented as something that people asked for. I feel that might be a misrepresentation people are desperate not to have to spend money out of their own pocket to get reports to qualify for the NDIS access in the first place. Anyone who could not want it ended up with a short six-month plan just to get diagnostics reports before they put on a plan that would actually assist. A better alternative would be to fund any reports required a change of circumstances or access. I also believe this is insulting to the adult professionals who have been working with plans around the country for years if their reports are not believed but someone who meets you for a few hours is believed and their recommendations are acted upon instead. It is very alarming that people have fluctuating conditions and we'll not be exhibiting those during the assessment and because his disability means launching new people into their lives is difficult. Being an NDIS participant is already a full-time job filling out forms chasing things up having to reach out your whole life story to one assessor because of a change of circumstances which is usually a stressful time anyway when you urgently need something and then conceivable level of stress which is unnecessary. That's a better alternative which would be workable is to have some funding available for any reports needed for either access or change your circumstances which doesn't need to come out of people's allocated plan budget if that is the NDIS who require the report. That way people's need to access reports and anyone who wants an independent report can get one, and everybody else can continue with the therapist who knows them well and the ones they have access to. Access is another critical point you can wait almost an entire plan duration to get to the top of the waiting list to see someone and then the only thing you achieve with them is to write a report, it would be more useful to finally get to that waiting list and receive the help you require. This suggests that there is not an overabundance of therapists out there to conduct these assessments.

24. Independent assessors will not be able to identify when the questioning they are using to measure a person's disability is inadequate, like someone known to the person would be able to do and then address.
25. Disabilities are personal. No two people are the same. To be assessed by an independent assessor, who does not know an individual and has no way of truly understanding each type of condition (e.g. Mitochondrial Diseases) cannot reasonably be able to make correct judgements.
26. Independent assessments are throwing our professional therapists and assessors under the bus. Those of us with people who already know us are going to be put into a position of facing strangers and once again proving our disabilities.
27. Lack of real knowledge and time spent to assess person properly.
28. No-one can understand the complexity of a disability in a person's life in less than four hours — that has been demonstrated when people had their first NDIS Plan — most people had to go through a review process, to get the right decision and to include all of the funding required to support the person with disability, and that was made with the information provided by medical officers in that person's life including treating specialists and surgeons, OTs and Physios. It is extremely unlikely assessors will have the diverse knowledge of the impact on an individual's life, for their own form/type of disability/ies each person has, as it is different for each person — there will never be an appropriate benchmark, that can be applied across the board, for each diagnosis — disability is individualised for each person. We are not a type of car, that can be identified by each model, and based on reported issues for each model. We are people. We are individuals. We have different needs that cannot be generalised or based on "commonly" applicable issues for each type of diagnosis!

29. No choice and control, strangers who don't have time to understand my situation, cookie-cutter decisions and random outcomes from luck with which assessor you are assigned. Choice, control, and continuity are critical. NDIS should pay for assessments but I should choose the provider myself.
30. The independent assessor would not know nor understand the participants compared to other specialists that have been seeing the participants for a longer time, in some cases years.
31. This is a dreadful way of assessing people and is bound to end in disaster.
32. They take longer to do, you have to pay extra money and they will probably not take reports from our service providers.
33. The IAs don't know me or my complexities. I should be able to be assessed by the Allied Health and other professionals who have been working with me for many years and know about me, how my body works, how my disability impacts on me, what a good day looks like and what a bad one looks like.
34. If they have no PREVIOUS KNOWLEDGE of the person their input will be assumptions.
35. Not knowing what's going to happen.
36. Just more paperwork.
37. Why do I have to keep proving my disability at every turn and having shoved in my face. I don't need reminded that I'm disabled and have societies' records they are free to examine upon request.
38. Disability needs cannot be based around assessment. Disability is very person-to-person and they need all the supports that they can get to live a normal life. The NDIS was not based around assessments.
39. For people with psychiatric problems, a specialist psychiatrist is required and conditions may not present at all times.
40. For many people it will just bring back the frustrations experienced before the NDIS when they couldn't get anyone to listen to pleas for support. It will particularly affect people with rare conditions and adults who have difficulty self-advocating and a sketchy documented history. The ramifications of that are enormous for the actual support of impacts of disability and of mental health. For our cohort, having an under-recognised, unsupported rare condition has meant a lifetime of misunderstanding for many people.
41. My limitations vary from day-to-day significantly..one assessment does not give a full picture.
42. When assessing someone with a disability a stranger or someone who hasnt worked with the person over time can't give a true picture of the needs of that person. I feel this is just another hoop to jump through to cut the cost of the NDIS.
43. My daughter has her own Occupational Therapists who know her well and have assessed her numerous times. What about choice and control.
44. Private organisations have a profitable interest in their outcomes — money is their bottom line and not necessarily the best outcome for the person being assessed. I am concerned this will impact on the overall outcome of their assessment.
45. Independent assessor can't have same understanding in a few hours as regular practitioners and the PWD do. Also may be traumatic/invasive going to through more assessments with a stranger.

46. The process to apply for NDIS is challenging enough with all the documentation and medical evidence that you need to supply.
47. I feel that the Assessors will Not have any idea of all disabilities and how everyone is affected differently and individuals' abilities, strengths and weaknesses. Assessments will add unnecessary extra stress on PWD.
48. You are being assessed by a panel of people who may or may not have experience of your condition, using a format of questions in a one-size-fits-all scenario, which it doesn't because even those with the same condition may present differently and are you being assessed on a good day or a bad day, as such blanket assessments don't even acknowledge that there is such a thing as a good or bad day.
49. I have a rare genetic disorder that has an average diagnosis age of 26 because it is so hard to spot and then treat. I have multiple specialists I see regularly I various medical areas and even then it's hard to find actual doctors that know a lot about my disability. It's not possible that some independent contractor from the Liberal Party's chosen company has ever even heard of my disease! Let alone have any idea what it takes to survive it daily.
50. The relationships developed over time with allied health professionals are essential to the quality of support for disabled people.
51. How can someone diagnose in four hours what a specialist has taken years to treat?
52. Too short, not undertaken by appropriately qualified, experienced occupational therapists (who are the only allied health to complete full functional assessments), won't work for multiple disabilities, especially shouldn't be imposed on people once on the scheme as the scheme is for *permanent* and significant disabilities, unfair, inequitable, wasteful as they won't fix the problem of disparate access, intrusive, inappropriate because we won't know the people assessing us who come into our homes!, not evidence based, not what Tune recommended, and zero community consultation, transparency, choice and control.
53. My medical professionals know my needs best.
54. These are not designed to support participants and applicants. We are the experts, as are our treating professionals. Sympathy bias is a lie, our lives are important and sustainability is a poor excuse for gatekeeping the scheme as it is already at an underspend.
55. I am regularly assessed via capacity-building daily activities yet another assessor-stranger is really unnecessary.
56. Applicants who have psychosocial disabilities need professional psychiatric assessment and evaluation of needs.
57. Why do we need to spend more money on assessments when I have a history of my Disability already recorded and on file as a person who was on DSP.
58. Simply, they promote the medicalised model of reducing people's individual stories to fit into boxes that can be ticked or crossed. There is no simple way! which is why the scheme was designed to be person centric and individualised. Also once a person has been accepted into the scheme, they should not be required to keep re-justifying their disability. Admission to the scheme already requires that the disability be lifelong.
59. The 'Independent Assessment' is funded by NDIS and therefore cannot be truly Independent.

The tests the assessor may use is not standardised to accommodate ALL pwd.

Assessment results will not be provided to participants — which causes stress and anxiety

for the participants who should have complete transparency on everything submitted on their person to NDIS.

Assessor should not invade participant's personal space in coming into pwd home.

Assessor cannot fully determine the participant's capacity in a 20-minute to one-hour meet. It's an invasion of privacy.

Independent Assessments are a way of negatively impacting on pwd..

Independent Assessments will be used as a judgement tool (because people are fallible) to determine who should or shouldn't access NDIS.

Anxiety and Stress forming that people will avoid getting the help they need from NDIS to avoid going through Assessment.

Without transparency in obtaining copy of the report, you essentially take away participants right to recourse/objection/negotiation and free will. Therefore there is no "choice and control" in Independent Assessments.

60. The assessments will be carried out by an Allied Health professional who may not know the specific issues that come with my physical disability. They will be using medically orientated tools for the assessment which require tick-box answers with little opportunity for an explanation or elaboration as to the reasons behind an answer.

61. It feels like yet another hoop to jump through, in a journey to access that is already extremely hard.

I had to apply three times for access and hound the NDIA for updates for almost a year. It was incredibly traumatic.

The one saving grace was that I retained complete choice about the providers that I dealt with. These are a team of allied health professionals who I trust implicitly, who understand me and my disability, and how it impacts my life. People I have worked with for over 20 years.

How can a brief assessment by a stranger in my home or online, using standardised tools compare to the depth of understanding gained from 20-plus years of patient-centred care?

Functional capacity cannot be addressed in a vacuum or without deep knowledge of patient experience in different contexts, and of the unique impact of the disability on the person's life, their history and treatment progression.

62. I think budget constraints will be reflected in reports in the same way R@N is considered in plans currently.

63. Choice and control.

64. Inconsistencies are likely to occur.

65. "Independent assessment" is a misnomer. Even the most impartial assessor has their own biases. Also, especially in the case of disabled people with complex needs, the best outcomes occur when there is a good rapport between the disabled person & their support team, including those who assess them.

66. There is no way we can be assessed by people who do not know us. That's what's being proposed. In addition, there's no way we can be assessed and our needs understood in 10 minutes. Having someone come into our homes is a huge breach of privacy and trust. Many of us have more than one disability and also trauma from clinicians and practitioners. A lot of us have been abused and need contact only with safe people of our choosing.

67. They don't take into consideration the variability of unusual disabilities.
68. The relationships developed over time with allied health professionals are essential to the quality of support for disabled people.
69. How can an independent know someone in one session. Most disabilities can be complex additionally a two-to-four-hour session would be too exhausting for most people.
70. It takes a great deal of time to become familiar with and assess the needs of severely disabled people. Many of the therapists our family member has have years of experience in his particular disability. Generalist-therapists do not have this.
71. Because people who don't know me will not be able to assess my capacity, I have spent years working with therapy teams to achieve good outcomes which will be undermined. Also, you devalue the work of therapists and the organisation that receives the contract WILL NOT BE independent.
72. Takes away choice and control.
73. I don't want strangers assessing myself or my child. Relationships are important in trusting someone and exposing your struggles. I want therapists who know us to do this.
74. Assessors are an additional stressor on people who are already coping with a disability and are particularly stressful for people who have a psychosocial disability or an acquired disability. For some people they are traumatic and triggering. They have an overtone of insurers trying to deny liability which focuses on the cost of the participant rather than supporting the participant.
75. Choice and control.
76. I think it's irresponsible to base whether someone gets support or not based on convincing someone they have never met before. Especially for things like MH or people who have had previous negative experiences of the health system (aka most people with a disability), it takes time to build trust and understanding and an independent assessment will be discriminatory against them just by how the system would work. Also there's no guarantee the person assessing would have the necessary knowledge of the person's diagnosis to be able to make a sound judgement. Previous experiences of independent assessment done badly (Centrelink) will further erode people's trust in the NDIS which is already not great for many (especially in psychosocial/that's the area I live and work in so it's what I know about most).
77. Because they are not independent and the IA assessors are recruited with the carrot of bonuses from Government. The current AAT cases have shown time and time again that the independent assessments are not done correctly and most are overturned because the current allied health professionals know the person much better. At the estimates hearing it was confirmed only 28% of IA surveys were completed and out of the 28% the website shows a high percentage of satisfaction so the figures are inaccurate and it doesn't say if the positive feedback had successful plans given. At present none of the NDIA staff can provide an explanation of reasonable adjustment so how can they provide an explanation as to why they accepted and utilised the IA even though they are not Allied Health. Furthermore, the NDIA do not currently meet the Service Charter or the Participant Improvement Plan so with regards to IA there are many questions and concerns. It is similar to the DSP assessment model at Centrelink and no one seems to be raising those issues or the correlations. For example, since the implementation of the DSP assessments, the numbers of people successfully receiving DSP have dropped significantly — it was a measure to reduce spending and this new IA is no different. All of the governments did

not anticipate the actual number of people with disabilities, the number of people with Psychosocial disability, Autism, ID, etc. So this way they can try and reduce the number of people on NDIS. They should be looking at the other issues that plague the scheme — community access are not always provided and the actual DDA itself allows this to occur (legal exceptions); education depts do not correctly advise the Community Engagement teams of children who have been turned away, reasonable adjustments can be deemed as unjustifiable hardship or having detrimental effects to the school, teachers, other students so they DO NOT have to be put in place. Another aspect is the money issued to group under grants is not actually being utilised in the way it is sold, many people who are not in receipt of a package do not get a free service with all providers who get a grant — many have a lot of out-of-pocket costs so the business can have a building or their own maintenance. There are much bigger issues that need to be addressed before IA are implemented and it starts with the actual NDIA staff and their lack of transparency, despite the service charter, they do not act with care and diligence which is against the APS Code of Conduct.

78. It is impossible for a clinician who has never met a person before to have a full understanding of how a person is impacted by their disability.
79. Already assessed by medical professionals — NDIS have no business doing this — Invasive, intrusive, embarrassing. Human rights and psychological issues.
80. They are ONE health professional, probably an OT, who doesn't know you and is not a specialist in your disabilities conducting a standardised assessment tool on you for between one and three hours. It really erodes the idea of 'choice and control' as you don't get to have the health professionals who understand you and your disabilities providing expert evidence to support your application to be part of the NDIS or your NDIS review. Their report on you will be key in deciding how if you are successful in applying to be part of the NDIS or how much funding you will gain. You will not be entitled to see the report they have written on you. It's very worrying especially for people with complex disabilities, or people with intersecting identities such as having a disability and being LGBTIQ/CALD/Aboriginal as this one professional will have very limited understanding of how these aspects interact with their disability.

■ Why 13% say independent assessments are a bad idea

1. There's no relationship between the PWD and the assessor, there's no way they will get an accurate impression in such a short amount of time. Also for those of us with less common conditions the inability to choose our assessor opens it up to an inaccurate report from someone who doesn't understand (or in many cases has even heard of) our condition.
2. Adds extra stress, uncertainty and burden for participants who have already 'proven' their disability with practitioners who are familiar with them, and who they are familiar with.
3. Please consider how such assessments are used in Accident Compensation. It is not beneficial for anyone but the insurers.
4. NDIS hasn't established itself as a centre of excellence which is fully accountable for fair decisive action. Why add another layer of effort for disabled people to have to make?
5. What is the rationale for these assessments? People who are on it already have been involved with allied health professionals the entirety of their disability, do they think people are lying about being disabled??
6. It removes the choice and control of participants. It's unclear and I don't want to have to see another stranger each plan.
7. The most appropriate people to do these assessments are the applicant's own medical and mental health professionals. Independent assessors may be useful, only for applicants who do not have an ongoing relationship with a medical or mental health practitioner. Independent assessors will need to be professionals who have additional tertiary qualifications in disability issues. I do not want to see the disability sector, once again, exploited by third-rate practitioners. I see the quality of the independent assessors in the workers compensation field and hope that NDIS applicants will be spared the angst of third-rate independent assessors. In summary: Applicant's own medical and mental health practitioners should be first option. Independent assessors only used when applicant hasn't had an ongoing relationship with their own medical or mental health practitioner. And then, there need to be a way of vetting out imposter assessors.
8. This all needs to be considered in context of the individual but what guarantee do we have that the independent assessor will have a knowledge of my particular disability — from my reading I find many of the questions in the IA to be intrusive, confronting, invasive re my private life when all the information they want to collect in my opinion is already with them. I fail to understand how IA will be supportive information re the services I need on a daily basis and the equipment I need.
9. There needs to be options for access and evaluation that don't cost money, due to widespread poverty amongst disabled people. When I took three years to gather the evidence I needed in a way that the scheme wouldn't reject, I needed someone to be paying for the expensive appointments I was making. I am on the pension (when I began the process I was on Newstart too) and I am sure I paid well over \$1500 in those three years for just the appointments where I asked specialists to write letters.

I firmly believe the current structure (which I have read up on thoroughly) is inadequate, and that a huge number of people — including people I know who are struggling without access to the NDIS — will fall through the cracks as a result. When people fall through the cracks they can and do die. Don't make the tests standardised in this way, and don't make this style of assessment mandatory for everyone.

10. Good idea at start — IF it provides more clarity on outcome than the current questions-without-notice the planner asks.
11. We go through enough pain and loss of dignity with our check-ups by specific (to our disability) medical professionals. It is abhorrent that we be asked to undergo an examination by an allied health professional who may have no specific knowledge on our disability. I was a nurse for 30-plus years before my injury-causing disability and medical professionals specialise in different areas and when you have a disability, you are under the care of a multi-disciplinary team, how can individual allied health professionals even compare with the knowledge of that team.
12. I don't think someone can understand a disabled person's needs through a one-off meeting/assessment. This is especially the case for people like me who have spent their life being misunderstood. For context, I am a 27-year-old with chronic illness and Autism Spectrum Disorder (ASD). I was misunderstood my whole life up until this year as just being quiet or introverted when it is a whole lot more than that. I have social and psychological support needs that are not understood by people who don't know me well. To the average person I am seen as "a quiet and independent high-achiever" — this does not do me any justice in relation to accessing supports.
13. Not all disabilities/capabilities can be adequately assessed by qualified experts in the space of three hours, especially some of the more neurological/behavioural/developmental conditions. Independent assessments shift another burden onto the shoulders of people with disabilities.
14. The only person I have seen support IA is Karen Burgess, even the AAT don't support them.
15. My own allied health professionals know my functioning and can track changes for good or bad. They know me as a person and can tell good days from bad days. An assessment procedure such as the one proposed is not independent as it is paid for by the NDIA and the assessors are drawn from a pool. There is a conflict of interest, it could also be used punitively in the manner that state workers-comp schemes have been known to do (see Four Corners).
16. The concept as presented thus far seems authoritarian rather than person-centred and collaborative. I understand the need for comparative validity of access/design of plans but very little choice in participation is being offered in this approach to assessment. I feel it's an economic strategy being disguised as helpful and cost-free to us. Also I have a post-grad degree in psychology in research validity. No matter the claims of what an assessment/survey is measuring, many are built upon structures that are inherently biased, racist and westernised in value-setting.
17. If assessments are functionally based, there are many anomalous levels of functioning, e.g. skills-splintering that only professionals who have witnessed these extremely varying levels of functioning can be in a position to assess, one example is how a person with extreme sensory or executive dysfunction as part of autism may have functional needs but ignorance assumes that intelligence somehow unknowns or can't exist beside so-called higher intelligence.

■ Why 13.7% are neutral on independent assessments

1. This could have helped me in my three attempts to get NDIS. Nevertheless, I don't trust this sneaky government.
2. Not good — like gov is doubting integrity of each service yet keeps each from getting lazy!
3. I think they could be okay if the people doing the assessments are experienced enough and take into account the point of view of your existing therapists — not just use them as a way to cut costs. I understand they are supposed to help people who might not be able to get assessments properly otherwise — and that is a good idea.
4. It depends who conducts the assessment. They must be experienced in the particular condition being assessed. I have been rejected from NDIS three times — maybe seeing an assessor would be better?
5. Honestly speaking, this is the first time I have heard of independent assessments. I know nothing about them.
6. I understand what the NDIA is trying to do and I think there is merit in them, but they are based on some very flawed ideas, and still are not addressing what needs to be done. In particular they are wanting another person to answer the Vineland for the person. If the person has no one who knows they are alive, the proposal is to put a support worker with the person for a shift and get them to answer the questions. Asking a parent to answer about a child is okay, asking a partner to ask about someone is okay, if the person is not being abused by them. What happens if it is domestic violence situation and the person tells a heap of lies. The school system in Victoria has teachers do the Vineland in relation to children with Intellectual Disability or Autism accessing funding for an aide, there are many cases when the teacher has guessed, can the child dress themselves or the like, because the teacher admitted they did not know the answer, the child is then denied funding in secondary school because the teacher assumed the child could do something without actually knowing if they could or not. Equally I do not doubt that there are people who are exaggerating their disability and I understand why they want another person answering some of the questions. But who is more likely to lie a parent or a partner, they want more funding. There are people who continue to see psychosocial disability as attention-seeking behaviour, without asking why is the person seeking attention in a maladaptive way? The NDIA already has the capacity to get information in other ways and does not do that. There is no whole-of-life plan for the person. Within the UK, the child would have health, education and social care all planning together. There are cases of parents saying things in relation to schools here, that schools themselves are not saying. The rich and well educated continue to get more. This is also what happened with final-year-of-school results in the UK this year due to COVID, teachers were asked to estimate, rich elite private schools had kids getting better marks than they had ever achieved before and those in government schools got worse marks than they had ever had before?? I know a case in Australia of the NDIA, where the person lived in a regional area, travelled to a capital city for a one-off assessment, that diagnosed autism, and they got into the NDIA on the basis of that assessment alone, would then only communicate with the NDIA via text message, saying they had not left home for years, had no family, no one knew if they were alive. They were allocated specialist coordination — who discovered the person was on Newstart and did not even have partial work capacity, was assessed and was meeting Centrelink participation requirements, was in a private rental and had moved multiple times in the last five years, equally how did they travel to the capital city, etc. What was really going on for the person was hard for anyone to tell. But there were different stories being told to different

people. I would also add that while Centrelink does capacity assessments, the difference is they can be appealed. While I can appeal an NDIA planning decision, I cannot appeal a functional capacity assessment decision. I also cannot ask for a new one because I am not happy with it, which I can do with Centrelink.

7. They are a good idea for my husband, who needs assessments we cannot afford, to get onto NDIS. They are a bad idea for my kids and myself who are already on NDIS, and would like to keep seeing our own allied health professionals, who know us, and are familiar with our rare condition.
8. It needs to be a one-on-one home-visit interview to observe the client in their natural surroundings and to keep them more relaxed. Assessors need to be open minded and do comprehensive research and assessments NOT just lump people into a tick-the-box categories assessment because these FAIL to take out-of-a-box issues into account and denies dignity and equality to people! I experience this issue often and have raised complaints with AHRC.
9. There times where they could be valuable to support the needs of people.
10. They could be very useful where NDIS applicants can't afford an assessment, however they should be covered by Medicare and must not be compulsory. Too many people can't afford to access the scheme which is a total disgrace.
11. My views, my voice.
12. Have not been able to get NDIS yet....on waiting list to have Mission Australia help me.
13. An assessment by an independent health professional only tells you so much, whereas your regular health assessor knows you very well.
14. Experience with assessments through Centrelink points to many issues, including people who are either not qualified or have no understanding of the disability issues concerned. I think it's just one more red-tape barrier vulnerable people have to jump through.
15. I think they are a good idea where they are voluntary, and enable access for people who need it, but do not have the evidence collected for access, and would otherwise be automatically excluded. They are an atrocious idea as a blanket measure, and as a review measure, and where other evidence is available. They should never be compulsory.

■ Why 6.2% say independent assessments are a good idea

1. From experience, NDIS has not seemed to be much focused into people's disabilities and provide tailored assistance. An independent assessment may give NDIS more clarity of what each individual needs and provide the necessary support to make the person worthwhile and achieve goals as it seems to be their aim and not necessarily met.
2. It will independently assess who is eligible and who is rorting the NDIS.
3. It may allow me to get NDIS where I have failed before. I had state funding but cannot get NDIS help.
4. Second opinion.
5. I think they are a good idea so long as social workers are better empowered to participate as providers, with the general and broad-based perspective we bring to PWD. I was disappointed the AASW initially said social workers and advanced clinical social workers would be easily integrated in the spirit of empowering people entering and benefiting from the Scheme. Initially NDIS heralded a bottom-up than the now top-down philosophy which has damaged the NDIS mission in my view. It seems vested top-down interests have resulted in this. People now find it very difficult to access the Scheme in the absence of general social worker uptake and service provision, as the Scheme became more restrictive, that essentially locked out most colleagues in favour of Accredited Mental Health Social Workers and specialist psychologists that has largely excluded general Accredited colleagues from item service areas, including myself. I am not speaking on behalf of the AASW here but rather to the upset and misleading promises we would be better integrated that has turned out to be the case. As a discipline largely concerned with enhancing social justice and people reaching full potential coupled with broad-based assessment and service-provision skills in the best interest of those we serve, I feel better engagement with generalists, many of whom have lived experience and very decent qualifications and person-centred experience has resulted in the low uptake and unnecessary barriers faced by people with disability like myself in accessing the Scheme and ask this be considered so as to better deliver quality support to applicants and participants alike, so the original philosophy of bottom-up service provision might be more fully realised than by those who seem to be monopolising the system as things stand. For instance, immediately NDIS assessors are advised I am an AASW Accredited member and accountable professional but not an AHHRA-registered health provider like say, a clinical psychologist or similar, they disengage from referring and never call again. This needs to be rectified in the best interest of the Scheme, participants and providers alike.
6. Gives better clarity to decision-making.
7. They provide a means for people who do not have the documentation they need to meet access to access specialists they can't afford to see.

They prevent a person's usual care team weighting their reports in favour of funding for their own services — e.g. an OT report that conveniently suggests increased funding for OT whether or not that's really what they need.
8. The current system puts a lot of pressure on participants to "prove" that they qualify for the NDIS. The guidelines are not clearly defined and the wording in reports becomes critical. It sets people up to fail if the professionals writing the reports are not familiar with NDIS criteria.
9. Everyone is different so people should be assessed as individuals.

■ Why 6.2% say independent assessments are an excellent idea

1. Having applied and been rejected twice, I felt like NDIS treated me like a number on a page.
2. Trying to compile adequate evidence to satisfy NDIS seems almost impossible, and I have concerns that the NDIS 'delegates' have little to no understanding of the issues that people (or parents of people) with disabilities have to battle every day.
3. Clients will get their opinions heard.
4. People are struggling to get evidence of impairment, capacity and performance to satisfy eligibility requirements, and relying on sources like GPs who don't understand disability and cannot communicate about functioning, only diagnosis.
5. To make things more transparent.
6. A tick-box approach will not address individual needs. This is just a cost-cutting exercise by the government.
7. Get an idea of how the NDIS can help the individual participant.
8. Not impressed with the current system which is very self-serving by some service providers.

Question 2 — How are the government's plans to start independent assessments making you feel?

People with Disability Australia asked the members who participated in our survey **How are the government's plans to start independent assessments making you feel?**

The majority of people felt unexcited, unhappy, anxious, defeated and overwhelmed at the government's plans to start independent assessments

Most of the 146 people who participated in the survey marked their feelings on a scale of 1 to 5.

Our scale counted 1 as strongly disagreeing; 2 disagreeing; 3 neither agreeing nor disagreeing; 4 agreeing; and 5 strongly agreeing.

We asked people about a variety of emotions they could be feeling about the government's plans to start independent assessments. These emotions included excitement, happiness, relief, indifference, anxiety, defeat and overwhelm.

What we found was the majority of people felt unexcited, unhappy, anxious, defeated and overwhelmed at the government's plans to start independent assessments. They were also not relieved and not indifferent.

A 79.4% majority or 116 people disagreed they were excited by the government's plans to start independent assessments.

The total proportion of people who were unhappy at the government's plans was 78.6%, or 114 people.

A 77.4% majority or 113 people disagreed they felt relief at the plans.

People felt passionate about the plans. A 67.4% majority or 97 people disagreed they felt indifference at what the government plans to do.

A 72.6% majority or 106 people agreed they felt anxious about the plans.

Most people — a 63.2% or 91-person majority — agreed they felt defeated at the plans.

In all, a 66.9% majority, or 97 people, agreed they felt overwhelmed about the government's plans to start independent assessments.

■ 2.1 — I (definitely do not) feel excited

All of the 146 people who completed PWDA's survey gave their views on the statement **I am excited about the Australian Government's plans to start independent assessments.**

The majority of people in the survey told us they were very unexcited about the government's plans to start independent assessments.

Their mean or average response was 2, meaning they disagreed with the statement they felt excited. The mode or typical response was 1 — they were very unexcited — with a massive 67.1% of people, or 98 participants, strongly disagreeing they were excited. Another 12.3% or 18 people disagreed they were excited. **All in all, 79.4% or 116 people disagreed they were excited by the plans.**

Some 14.4% of people, or 21 people, were neutral on whether or not they were excited.

A minority of people were excited with the plans to start independent assessments — 2.1% or three people — while another 4.1%, or six people, were very excited with the government's plans. In total, 6.2% or nine people excited with the plans.

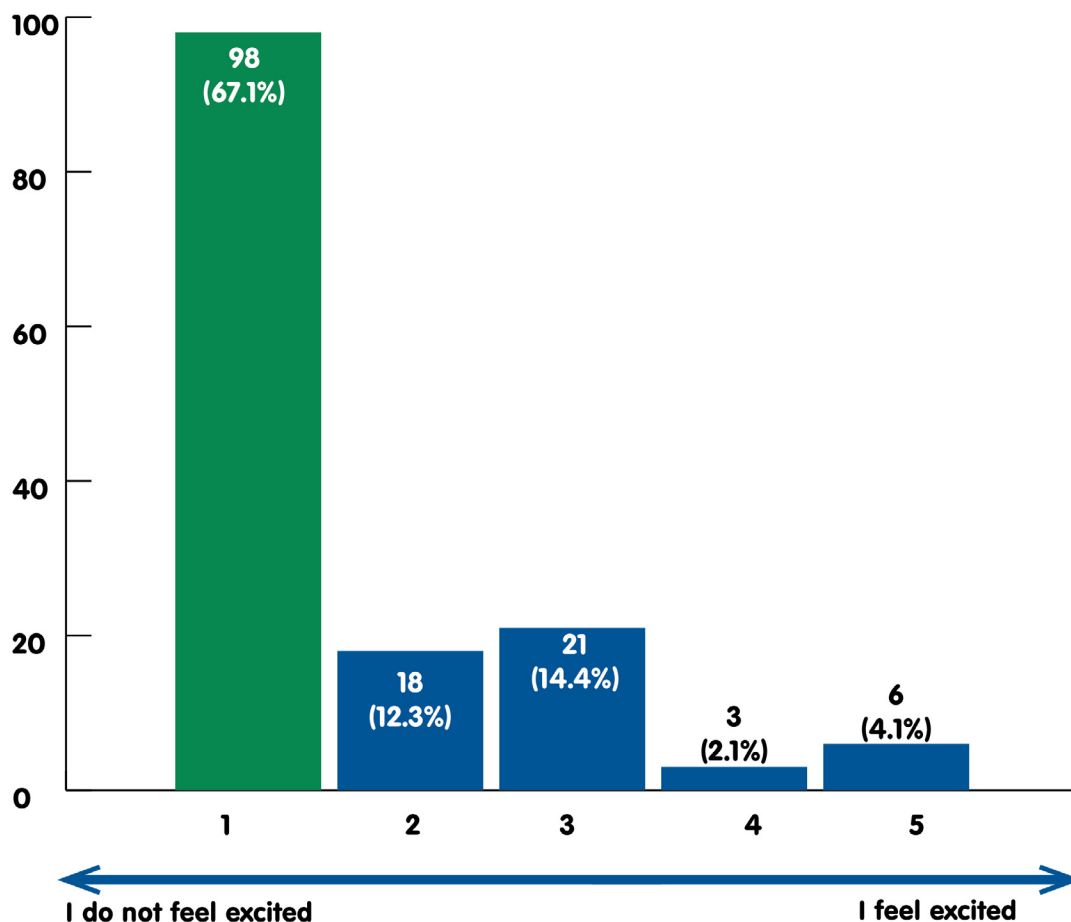


Figure 2 — A green column in a chart shows a 67.1% majority of people in PWDA's survey did not feel excited about the Australian Government's plan for independent assessments.

■ 2.2 — I (definitely do not) feel happy

A majority 145 people of the 146 people who completed PWDA's survey gave their views on the statement **I feel happy about the Australian Government's plans to start independent assessments**.

They weren't happy, Jan.

The mean or average answer was 2, meaning they disagreed that they were happy with the government's plans. The mode or typical response was 1, with 64.1% or 93 people saying they strongly disagreed they were happy with the plans. Another 14.5% or 21 people disagreed they were happy. **The total proportion of people who were unhappy at the government's plans to start independent assessments was 78.6%, or 114 people.**

Some 15.2% of people, or 22 people, were neutral on whether or not they were happy.

A minority of people were happy with the plans to start independent assessments — 3.4% or five people — while another 2.8%, or four people, were very happy with the government's plans. In total, 6.2% or nine people were happy with the plans.

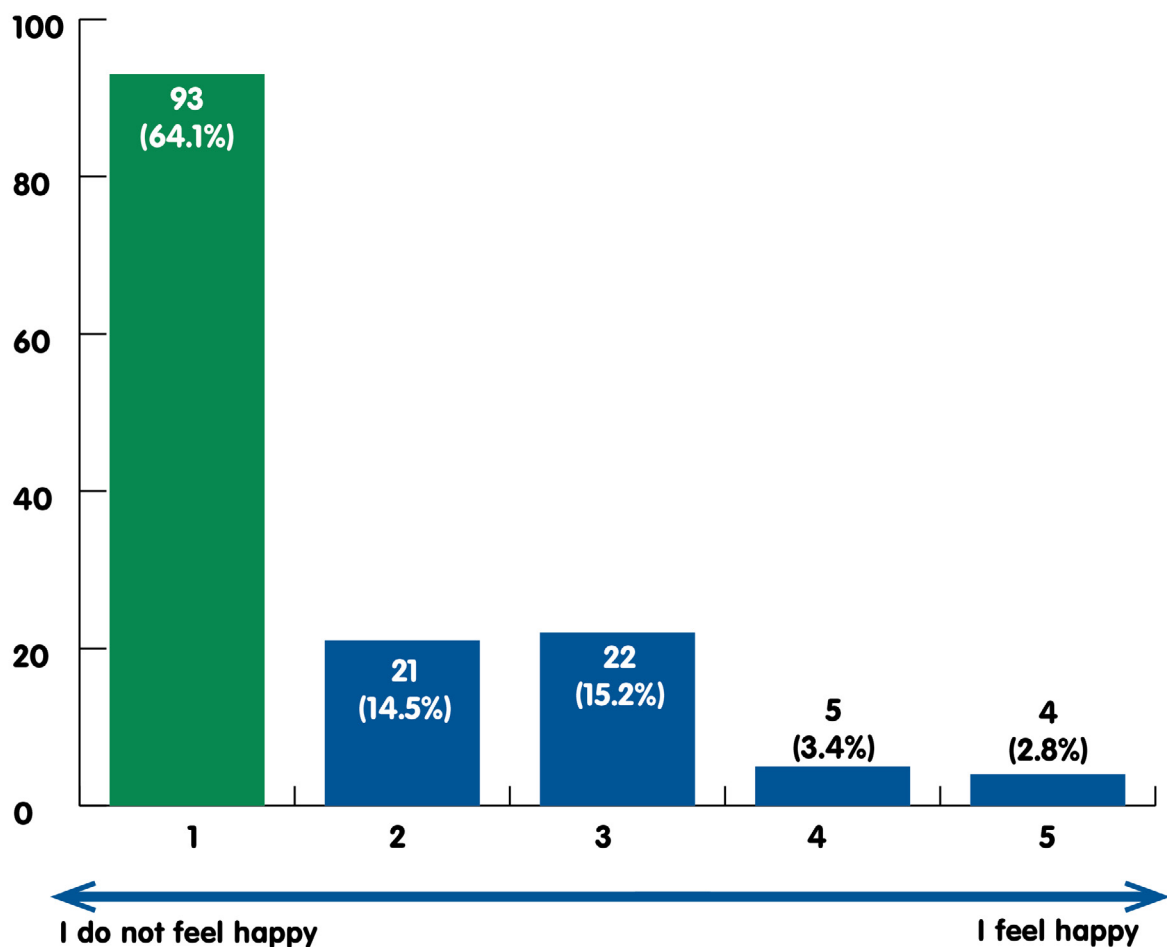


Figure 3 — A green column in a chart shows a 64.1% majority of people in PWDA's survey did not feel happy about the Australian Government's plan for independent assessments. assessments.

■ 2.3 — I (definitely do not) feel relieved

All of the 146 people who completed PWDA's survey gave their views on the statement **I feel relieved about the Australian Government's plans to start independent assessments**.

Most people did not feel relief at the government's plans.

The mean or average response was 2, meaning people disagreed they felt relief. The mode or typical response was 1, with 67.1% or 98 people strongly disagreeing they felt relief. Another 10.3%, or 15 people, disagreed they felt relief. **In all, 77.4% or 113 people disagreed they felt relief at the government's plans to start independent assessments.**

Some 14.4%, or 21 people, were neutral on whether they felt relief at the plans.

Another 4.8% of people, or seven people, agreed they felt relief, while another 3.4%, or five people, strongly agreed they felt relieved. Only 8.2% of survey participants, or 12 people, felt relief.

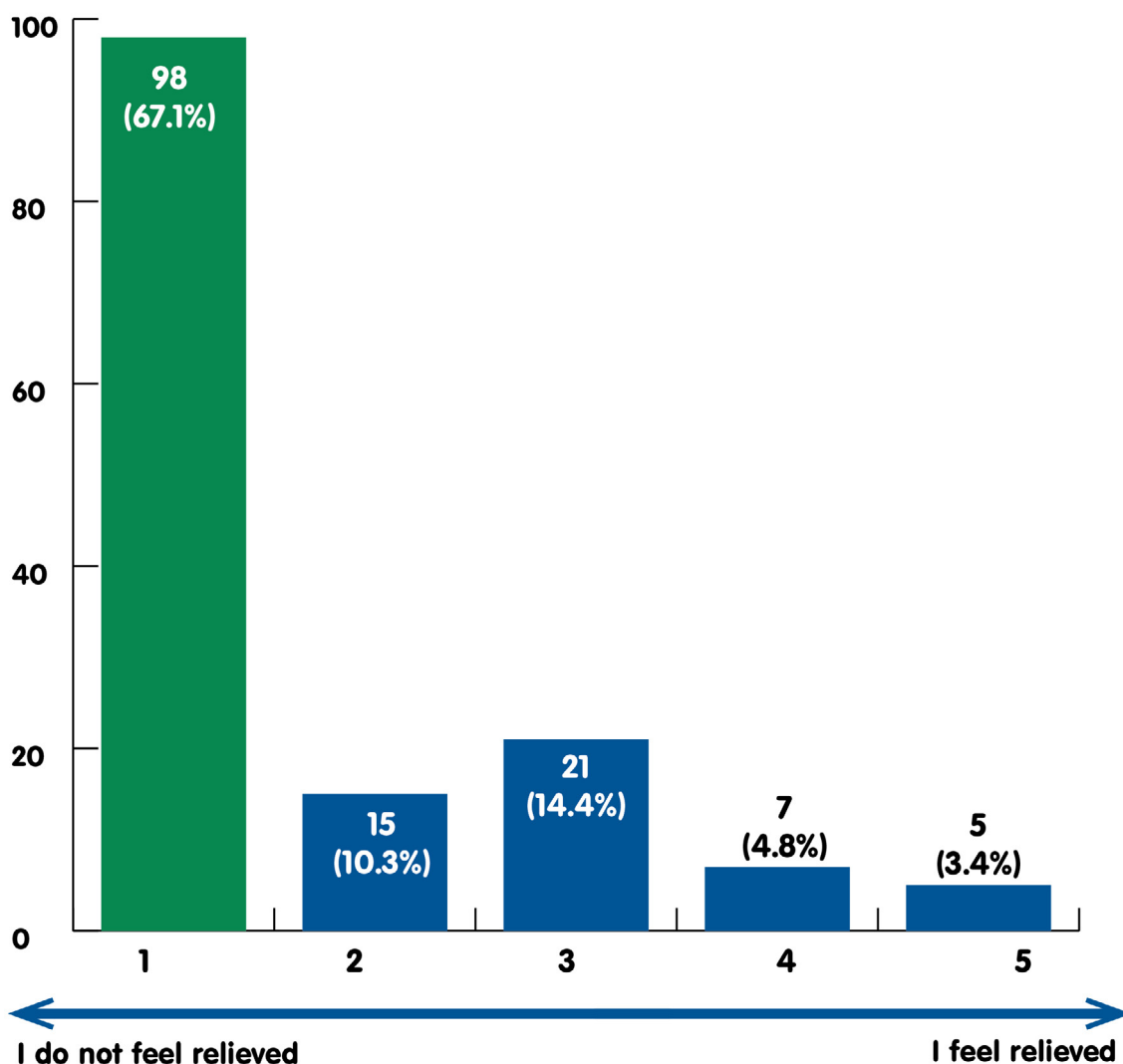


Figure 4 — A green column in a chart shows a 67.1% majority of people in PWDA's survey did not feel relieved about the Australian Government's plan for independent assessments.

■ 2.4 — I (definitely do not) feel indifferent

A majority 144 of the 146 people who completed PWDA's survey gave their views on the statement **I feel indifferent about the Australian Government's plans to start independent assessments**.

Most people did not feel indifference at the government's plans.

The mean or average response was 2, meaning people disagreed they felt indifference.

The mode or typical response was 1, with 53.5% or 77 people strongly disagreeing they felt indifference. Another 13.9%, or 20 people, disagreed they felt indifference. **All in all, 67.4% or 97 people disagreed they felt indifference at the government's plans to start independent assessments.**

Some 16%, or 23 people, were neutral on whether they felt indifference.

Another 7.6% of people, or 11 people, agreed they felt indifferent, while another 9%, or 13 people, strongly agreed they felt indifference. A total of 16.6% of survey participants, or 24 people, felt indifference.

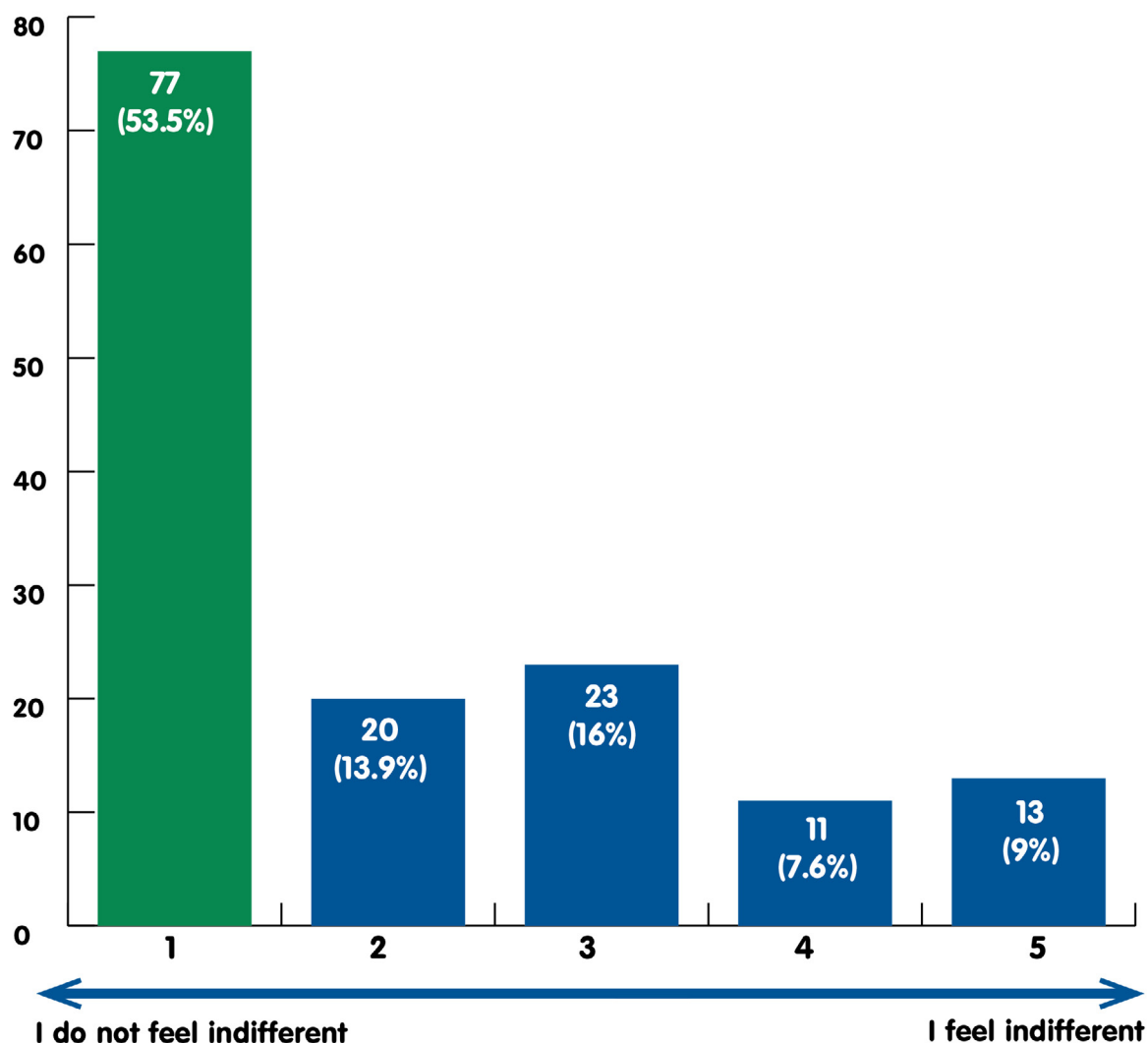


Figure 5 — A green column in a chart shows a 53.5% majority of people in PWDA's survey did not feel indifferent about the Australian Government's plan for independent assessments.

■ 2.5 — I definitely feel anxious

All 146 of the people who completed PWDA's survey gave their views on the statement **I feel anxious about the Australian Government's plans to start independent assessments**.

The government's plans to start independent assessments make most people anxious.

The mean or average response was 4, that people agreed they felt anxious. The mode or typical response was 5, with 56.2% or 82 people strongly agreeing they felt anxious. Another 16.4%, or 24 people, agreed they felt anxious. **In all, 72.6% or 106 people agreed they felt anxious about the government's plans.**

Some 11%, or 16 people, neither agreed or disagreed they felt anxious about the plans.

Another 6.2% of people, or nine people, disagreed they felt anxious, while another 10.3%, or 15 people, strongly disagreed they felt anxious. A total of 16.5% of survey participants, or 24 people, said they did not feel anxious.

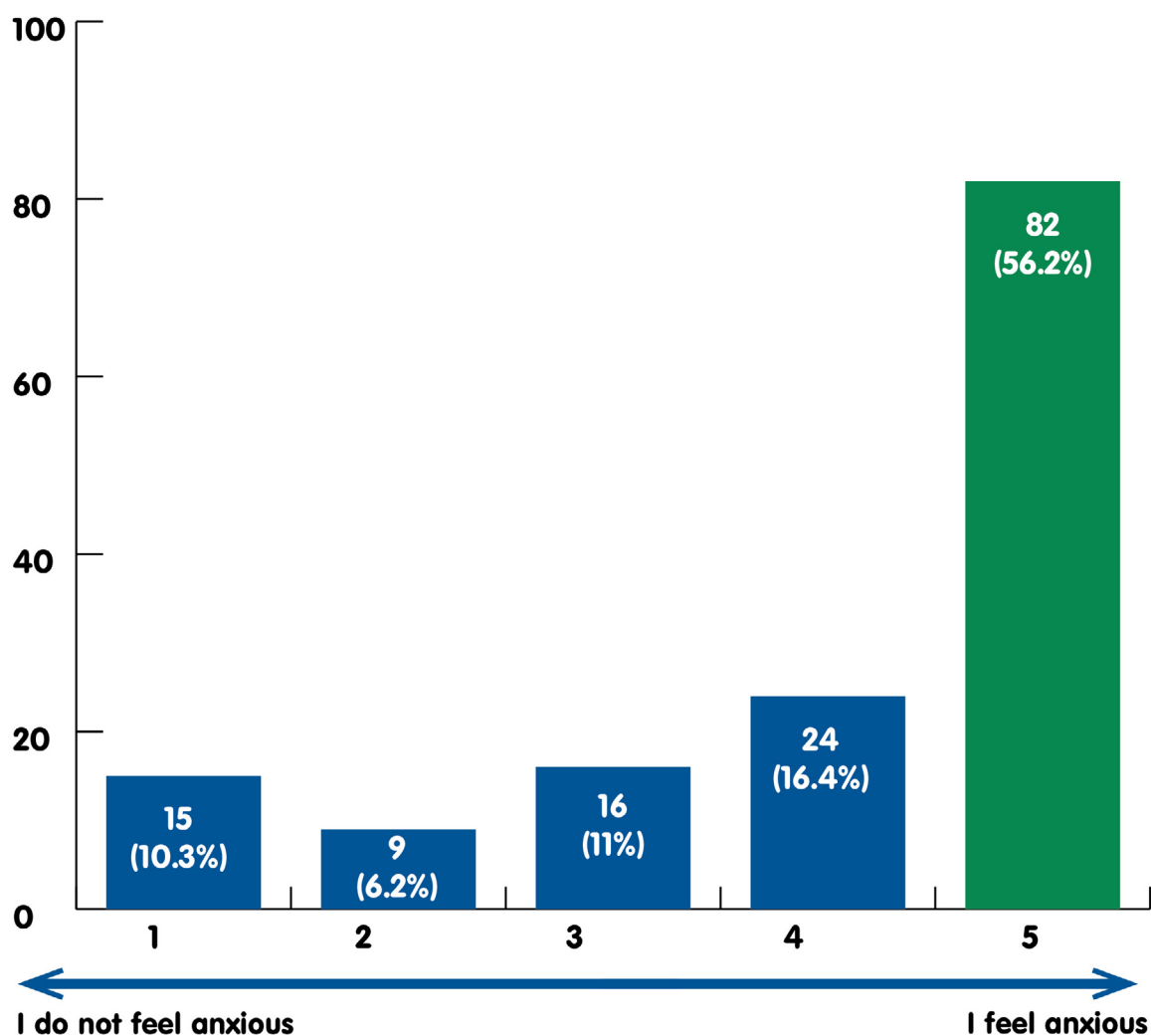


Figure 6 — A green column in a chart shows a 56.2% majority of people in PWDA's survey felt very anxious about the Australian Government's plan for independent assessments.

■ 2.6 — I definitely feel defeated

A majority 144 of the 146 people who completed PWDA's survey gave their views on the statement **I feel defeated about the Australian Government's plans to start independent assessments**.

The government's plans to start independent assessments make most people feel defeated.

The mean or average response was 4, that people agreed they felt defeated. The mode or typical response was 5, with 48.6% or 70 people strongly agreeing they felt defeated. Another 14.6%, or 21 people, agreed they felt defeated. **All in all, 63.2% or 91 people agreed they felt defeated about the government's plans.**

Some 18.8%, or 27 people, neither agreed or disagreed they felt defeated about the plans.

Another 11.8% of people, or 17 people, disagreed they felt defeated, while another 6.3%, or nine people, strongly disagreed they felt defeated. A total of 18.1% of survey participants, or 26 people, said they did not feel defeated.

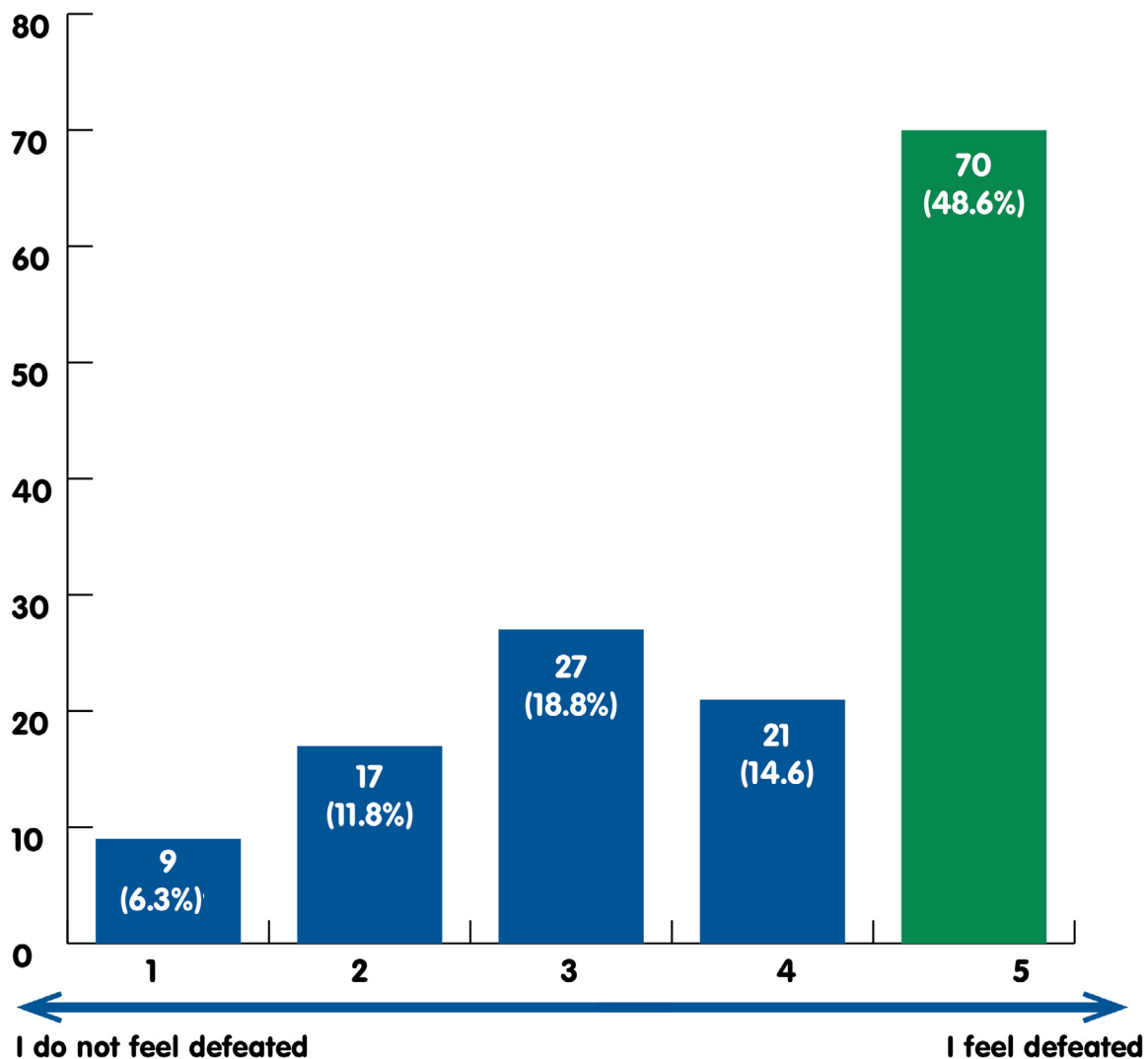


Figure 7 — A green column in a chart shows 48.6%, or the biggest group of people in PWDA's survey, felt very defeated about the Australian Government's plan for independent assessments.

■ 2.7 — I definitely feel overwhelmed

A majority 145 of the 146 people who completed PWDA's survey gave their views on the statement **I feel overwhelmed about the Australian Government's plans to start independent assessments**.

The government's plans to start independent assessments make most people feel overwhelmed.

The mean or average response was 4, that people agreed they felt overwhelmed. The mode or typical response was 5, with 48.3% or 70 people strongly agreeing they felt overwhelmed. Another 18.6%, or 27 people, agreed they felt overwhelmed. **In all, 66.9% or 97 people agreed they felt overwhelmed about the government's plans.**

Some 16.6%, or 24 people, neither agreed or disagreed they felt overwhelmed about the plans.

Another 11.7% of people, or 17 people, disagreed they felt overwhelmed, while another 4.8%, or seven people, strongly disagreed they felt overwhelmed. A total of 16.5% of survey participants, or 24 people, said they did not feel overwhelmed.

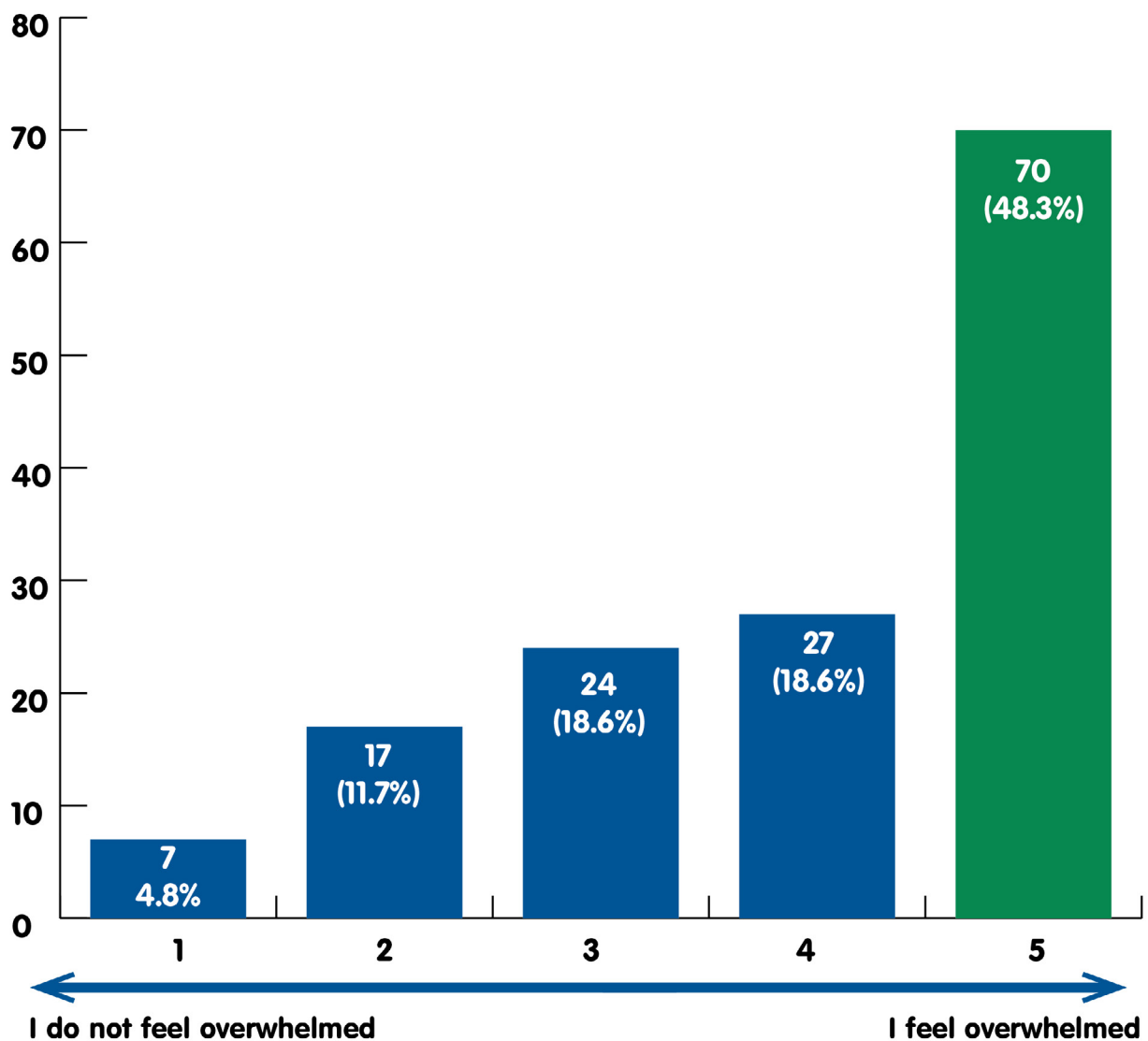


Figure 8 — A green column in a chart shows 48.3%, or the biggest group of people in PWDA's survey, felt very overwhelmed about the Australian Government's plan for independent assessments.

■ 2.8 — Please add any comments you may have

Seventy-five people, or 51.3%, of the 146 people who completed PWDA's survey about how people felt about the Australian Government's plans to start independent assessments shared more about their feelings on the plans.

Some people were very distressed at the government's plans and we share their views here, with permission.

Content warning: a number of people with disability shared they felt suicidal when thinking about independent assessments and were extended support by PWDA. If you have suicidal thoughts, you can call:

- Lifeline (24/7) on 13 11 14.
- Suicide Callback Services (24/7) on 1300 659 467.
- Mensline (24/7) on 1300 789 978.

■ 2.8 — Additional comments (51% of the survey took part)

1. The whole NDIS process unfairly favours educated and highly literate and articulate people — the whole idea of reviews is horrible anyway, let alone having to be assessed by someone who has no idea of your day-to-day challenges — they will probably just be LNP donors after some ROI anyway.
2. I am terrified this is just another way to assess us out of the scheme, the same way they assessed 30,000 disabled Australians off the DSP! We are people and we deserve to have our human rights respected.
3. Certainly stressful.
4. I'm really scared I'll lose my NDIS and now I'm paranoid and preparing for how I could possibly maintain my wheelchair for longer than its intended life span. I'm scared to use support workers, because if I can lose all my support I would rather live a bad life than build a better one that could be ripped away from me. I feel ripped off. I paid a lot of money for assessments to get into NDIS thinking it would be worth it, basically it will support me for life but now they say the plan reviews can refer to access team and kick me out? They broke the promise. I feel like the LNP has stolen my money through these lies.
5. There needs to be a good professional relationship to build trust. An independent assessor would not be able to provide this in the timeframe allowed by NDIS.
6. I feel like this govt makes every effort to make getting assistance more difficult.
7. Still waiting since July to get appointment like I said before.
8. This is not the NDIS that was promised ... this is dehumanisation and will lead to cost savings and catastrophic outcomes for the high-need complex PWDs. I guess more will go to nursing home at a young age and the NDIS will be happy they are off their budget.
9. The community has been injected with a fear that has everyone panicking.

We know what this means. It means having to justify everything to strangers to have some semblance of a reasonable life.

It means anguish.

It means spiralling into depression.

It means feeling guilty about something that we shouldn't be feeling guilty about.

It means overexplaining and feeling like shit.

It means inadequate, uncaring, pious strangers controlling our lives once again.

For some, a return to this will be too much.

10. Although I'm very much in need of more supports I haven't even engaged with the NDIS so far as I just don't have the energy to jump through all the hoops. It is too complex, too bureaucratic and labyrinthine, and seems designed to deter people from even engaging. And I say this as a highly educated person with a master's degree.
11. It is frightening. We have seen new therapists to the field recommend ridiculous equipment and programs. Effective relationships with client and families over time are essential and economically good. Time to correct faulty equipment is costly.
12. It's another maze for use to navigate.
13. This is a misrepresentation of the recommendations in the Tune review.
14. The prospect of these assessments is terrifying. Especially for those of us who mask heavily without realising or if we happen to have a rare good functional day on the day of assessment.

I'm so afraid of losing our supports, a decent quality of life is not achievable without them. This is a breach of our human rights. They're treating us as liars and criminals, it's devastating.
15. Independent assessments ensure my disability and my support needs will remain hidden.
16. It is yet another way for this government to punish people with disabilities.
17. NDIS was a government project that held so much promise. It has turned into a nightmare to get on and with life-long disabilities there is not going to be major changes in care needed when person has a severe intellectual disability. We should always try and not give up but also be realistic. Why do we have to go through all of this when they already went through it to get disability pension.
18. As a person with disability and also a professional disability advocate, I am dreading the foreseeable time and money wasted, and potential trauma, this solution, organised in this one-size-fits-all approach, is likely expose participants, prospective participants, informal supports of people with disability, Allied Health professionals, and advocates alike too.
19. The AAT has already stated that professionals need to have a long-term view of a participant, this new system will discriminate against people who don't have easily identified labels for their disability.
20. I have read NDIS documents that claim that allied health professionals like mine may have "sympathy bias" towards their clients, which may be impacting the impartiality of their assessments.

What guarantee is there that contract workers employed by the NDIA won't have sympathy bias to the NDIS and a list of KPIs seeking to cut costs?

The NDIS is underpinned by the notion of choice and control. This proposal makes me feel utterly powerless. I believe it's real motivation is to kick people off the scheme.

I have dealt with work over and had extremely poor independent access Mehta which failed to take my disability into account when making recommendations for improvements to my workplace. These were "improvements" which my treating physio said were totally inappropriate because of my existing disability.

I fear more of the same from independent assessments.

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21. I feel suicidal.

22. I already have issues with how the reviews are done. I constantly have to fight with LAC etc.. FOR FUNDING. It's ridiculous that it's a different person every time.

23. Please refer to answer to question 1.

24. I feel its regressive in that it seeks to disempower pwd as having expertise in their own lived experience, it appears to privilege allied health professionals' judgements of us — harking back to the premise of a medical model. That is distressing and reductively dangerous.

25. If truly about providing financially neutral assessment options, just reimburse participants for any report fees, thus allowing us choice in presenting our evidence.

It's it clear how they will work or if it is really any different from what we have now. Clearly most people with a disability are against. They need to be heard.

26. I have gone through the anxious and painful process which adds more physical and emotional pain of requesting a review of my plan and initially have been successful. In the new plan the Delegate has removed crucial services that a previous Delegate has recognised and again I was encouraged to go again over the same process of a review. The fact that a person has a disability and in many cases more than one that makes life hell as my case is, it is very disheartening to realised that the NDIS which has been set up to help would find reasons not to accept disabilities or reasons to provide a helpful plan. In any case, from information received from NDIS this independent review may apply for people applying for the first time and if that is the case I could not access.

27. I don't want another government instrument deciding my capacity with unrealistic expectations under the guise of Scheme sustainability rather than providing a person-centred service

28. *As per my previous more detailed comment.

29. I have finally had the strength to start applying for NDIS for my children and me. It all feels hopeless now. I was already anxious about this process, but now I feel we will all be categorised according to things we can do some of the time, rather than being supported in a holistic way so we do not keep getting into crisis when we cannot meet expectations of others. My children and I are in a constant cycle of breakdown and burnout because we are not supported to work, maintain our housing, keep up with health appointments and medication or have stable relationships. From the outside looking in, we all live 'independently' and work part time.

30. I honestly feel that applying for the NDIS and having a planning meeting is challenging and overwhelming enough. Plus the additional OT reports needed for each yearly review is already challenging and time consuming. NDIS participants shouldn't then have further intrusion into their lives.

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31. I think I answered it in the first part, so many things that are left to be answered, so much confused.
32. I feel that my experience and type and level of needs are not fully understood and minimising happens when so-called professionals think functioning types is limited to one and can't handle a very differing level of functioning across different areas.
33. Expertise and empathy are the key factors in a successful outcome. How will this be achieved with the proposed process!!
34. I am terrified by the prospect of this happening. I do not trust that this will be a good thing. I am suicidal over this proposal.
35. The idea that someone can judge lives based on short and new interactions and impact our supports is very concerning.
36. Why should we have to prove the existence of our conditions and need for support in a way that assists us as individuals, not in a she-as-xyz, therefore she will get abc with no consideration of the individual's circumstances.
37. The questions are more revealing than any responses you'll get from them. Seriously, who wrote this survey? Biased at the outset.
38. This appears to be returning to a CaP and rationing system.
39. I feel this government (and probably Labor too) sees the NDIS as a waste of money and will start shunting people off like the DSS. For a while there things looked optimistic, not perfect but fixable in time. This is not a solution, it's an added burden. I hope the new board ensures there's lots of noise about this from the PWDA because the current response has been too quiet and too late.
40. Having to perform for a stranger that only looks for part of your day is daft. Putting myself at risk to do tasks to prove my disability come from some that care more about bean-counting than people.
41. It depends on how the model works — it is not working for people with ME/CFS now.
42. Four hours is far too long. For me personally it will exhaust me and I'll spend at least three days recovering from it.
43. As I do not know the details, and how it could help/hinder my next application to NDIS, I do not even know if this change (from past experiences) is going to help me?
44. It feels like being asked to prove yourself worthy after you've already gone to great lengths to do so. It's a waste of taxpayer money. It seems to assume you're trying to game the system when you just want access to adequate care.
45. I feel terror and despair.
46. Don't trust this government to do the right thing based on their track record.
47. I feel like any progress I have made would be undermined by this form of assessment.

It is so unfair and judgmental — we need choice and control — we know what it is we need to live and be able to participate in and live an inclusive life.

48. I need to see to believe any positive action is being had. Governments are good at lying and smoke-screening!
49. This is yet another example of the government and NDIA moving the goalposts and making the process way more complex than is necessary.
50. I feel anxious and worried that I will be required to undergo yearly independent assessments with a stranger who I will have to justify my needs for supports to. It also worries me very much for others who may struggle to self-advocate for their needs.
51. Stop trying to control people with disabilities.
52. The Government has not considered the additional impact this will have on everyone especially the Participant, Carers and the Plan Nominees. Additionally they are utilising the NDIS to create more jobs but if they reduce the number of participants the jobs will not be out there. Cost effective measures should be implementing a bucket of money not separated, train your staff, utilise online services better so you don't need to see someone for a review — it could easily be done on an online platform. Reducing the need for staff — we already know that the government uses KPIs and formulas to determine how much money the person will get regardless of reports, etc. provided, we also know that offices will sit around and chat about cases and determine themselves (despite the evidence) that a person is complex or not. So put all of this into online and you will save money because you don't need as much staff. I also know many staff are working weekends and claiming Overtime when it is not required. But the chasing around for participants, carers and plan nominees and advocates will increase anxiety and stress and I have no doubt this will be raised as a class action and in the disability commission. The NDIA have not been very accountable within the estimates nor are they subject to the Defective Administration Scheme so they can actually get away with treating participants, carers, plan nominees, providers, etc. poorly. This is why the IA will be implemented as it doesn't cost them as much as everyone else to go to the AAT and they can fund the best legal teams around whereas everyone else cannot nor should they have too.
The scheme was not created for this.
53. Who wants to go through a gruelling assessment that could last for four hours with people that don't know you or your history.
54. Independent assessments are a TERRIBLE idea. In the name of saving participants costs on getting reports (which NDIS funding can be used for anyway) it is ridiculous to put participants through the anxiety and stress of having to explain and justify themselves to yet another stranger and doesn't accord with a participant's choice and control.
55. This assessment is unlawful on a number of grounds, 1 you cannot base a disability around a set of guidelines, 2 you are creating mistrust into the system which is already being looked at by a royal commission.
56. I feel angry and confused. Like "what the hell are they doing?"
57. I feel like a performing seal being made to prove my disability for those who have an ideological fetish about punishing those of us who are a PWD. Are poor and unable to fight such bullshit. The report from the PC about how many S100 reviews are (forced to close) finished with no reason is alarming and will also be a part of this process.
58. I am incredibly disappointed to see where this NDIS is heading. It was so exciting to be at PWDA in 2013, knowing the voice of PWD were loud and stridently pushing for an NDIS

with bipartisan support. When Julia Gillard made the announcement and mentioned the work of then President Craig Wallace (Her comments are at 10.40 minutes, <https://www.youtube.com/watch?v=d8Z0MXRIOTw>), it was a fantastic piece of advocacy work! This thing we worked so hard to bring into play to benefit PWD across Australia has turned into this horrible feral animal.

59. I feel hurried — I have to get as much out of my first plan as possible because I have a history of being disbelieved due to poor assessments done by people who don't know me so I'm resigned to being kicked off the scheme at some point in the future as a result of the independent assessments.
60. The notion of bringing in these people causes me great anxiety.
61. It is in times of economic downturns when the most vulnerable have to be the most fearful. All kinds of funding cuts are more easily sellable to the voters/taxpayers under the campaign banner of needing to pull together and tighten our belts for the good of the nation.
62. Once accepted onto NDIS that should be it, unless someone is rorting the system.
63. It's already hard enough to feel like I have security of support on NDIS because with every review the chances that I will get necessary funding support cut is always there, and I know that without that support my capacity to appeal these decisions is limited without an advocate, and there simply aren't enough advocates to go around (especially MH-specific ones in Vic, there's basically nothing since the major one focuses on people on or under threat of compulsory treatment orders).
64. The thought of someone (even a panel of people) who does not personally know me or dealt medically with my physical challenges and would be ignorant of my physical condition and my needs, is insulting, insensitive and I feel quite concerned that incorrect judgements would be made.
65. I feel angry that the scheme which disabled people fought so hard to give us the services and supports we actually need is being eroded and threatened.
66. No choice or control in an Assessment that lacks transparency and is forced on a participant.
67. Where does this give participant choice?
68. Just the prospect of these assessments has been triggering anxiety and flashbacks. It goes against the principles of the NDIS and calls the participant's own medical practitioners' advice into question for no purpose. Where a participant has submitted documents from qualified medical practitioners it makes no sense — except if the NDIS is trying to find reasons not to support participants or to cut their supports.
69. I feel my choice and control is being further undermined by too much bureaucracy.
70. I think I have confidence in my ability to advocate for myself. But I do feel a bit uncertain about it.
71. There is a sense of mistrust and fear that the professional tone of the scheme is being eroded.
72. Having an anxious time in an assessment may have negative repercussions. I feel that it would send me backwards when I'm only now having confidence to go forward. I feel that my usual health professional knows me better but if I have to, I will do it. Thanks.
73. So bloody worn out. Like this system wasn't hard enough already. Terrified.

74. Pointless! The NDIS can't even get what they are doing right. The focus should be on proper administration. Government should be assessing Dole bludgers before people with a disability. Government salaries and pensions should be reduced in line with the rest of the world.

Question 3 — Have you had an independent assessment?

Among the 146 people who completed PWDA's survey, a 145-person majority told us whether or not they have taken part in the Australian Government's initial piloting of independent assessments for the NDIS.

Of those 145 people, five people — or 0.4% of our survey — told us they had taken part the NDIS independent assessments pilot program.

Some had a positive experience, others a negative experience. Their views are below.

Of those 145 people, five people – or 0.4% of our survey – told us they had taken part the NDIS independent assessments pilot program

Have you had an independent assessment as part of the NDIS assessment pilot program?

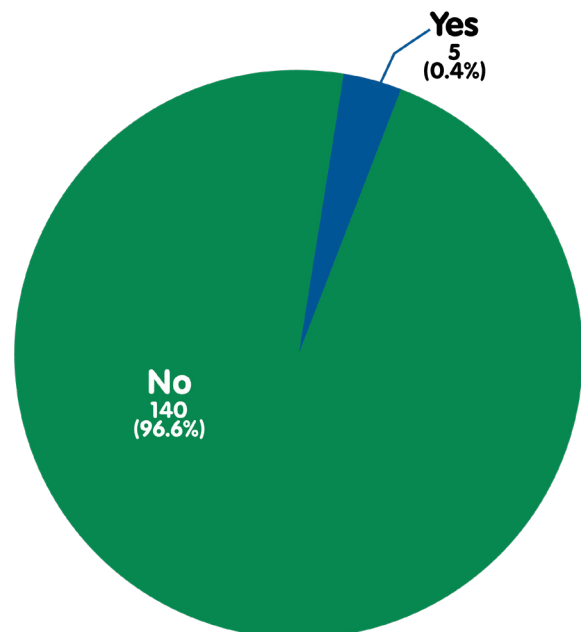


Figure 9 — A tiny slice of blue in a mostly green pie chart shows only 0.4% of people have had an NDIS independent assessment.

If you have independent assessment as part of the NDIS independent assessment pilot program, what did you think about the independent assessment (i.e. happy, unhappy, was it fair, did you feel heard?) (from 0.4% of people surveyed)

1. Disappointed and discriminated against! I'm not a disability category! I'm an individual that has suffered from a previous life-ending injury...
2. The interviewer lacked knowledge and experience and a lot of the time was spent educating her.
3. Happy with the assessment.
4. I think I was heard.
5. No comment.

Question 4 — Are you planning to take part in the second pilot of independent assessments?

A majority of 145 people of the 146 people who completed PWDA's survey noted the Australian Government had called for volunteers for the launch of its second pilot on independent assessments. They shared with us their views on whether or not they were planning to participate.

Twenty people, or a minority 13.8% of the people giving their view on the question, said they planned to take part in the second pilot of independent assessments.

The latest pilot is considered the second pilot by the National Disability Insurance Agency, although another pilot once known as the second pilot started early this year but was terminated early on because of COVID-19 shutdowns.

Sixteen of the 20 people or 80% of the people who planned to take part in the latest pilot said they would be willing to talk to PWDA more about their plan to take part.

The government has called for volunteers for the launch of its second pilot on Independent Assessments. Are you planning to participate?

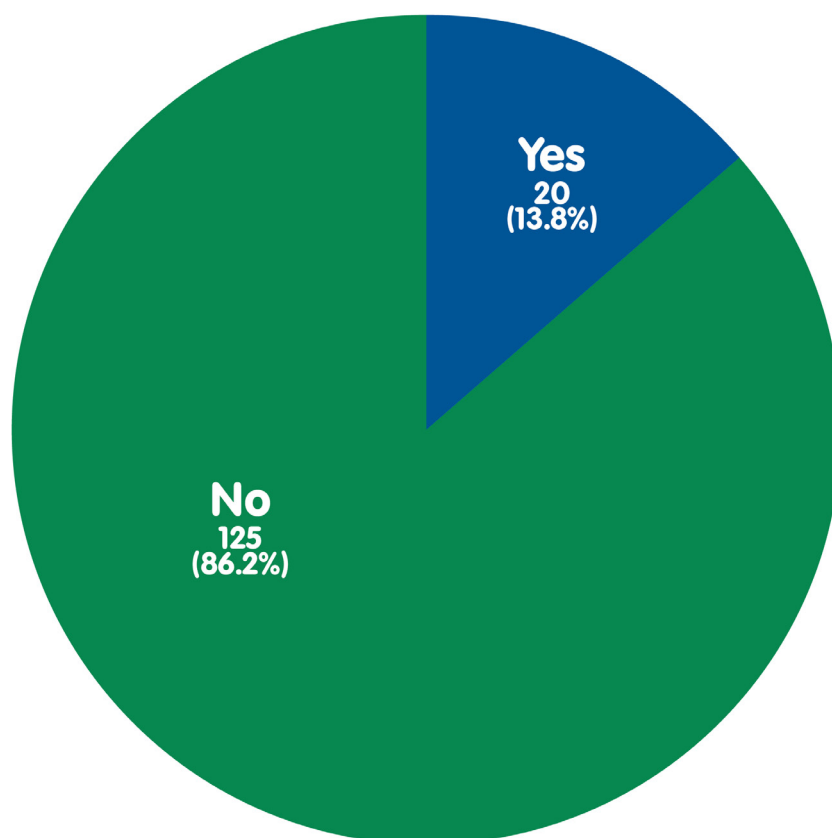


Figure 10 — A small slice of blue in a mostly green pie chart shows just 13.8% of people plan to have an NDIS independent assessment in the latest pilot.

Question 5 — Have you undergone an independent assessment in any other scheme?

One hundred and forty-four people of the 146 people who completed PWDA's survey answered our question **Have you undergone an independent assessment in any other scheme?** (e.g. workers compensation, transport/motor or Disability Support Pension schemes).

A significant 69 people, or 47.9%, had undergone an independent assessment as part of a scheme

A significant 69 people, or 47.9%, had undergone an independent assessment as part of a scheme. Another 17 people, or 11.8%, said they were not sure if they had experienced an independent assessment in a scheme. We acknowledge this group could include people who were not sure if they had been evaluated by an independent assessor and about eight people (see next question) who were potentially not sure if the assessor who evaluated them was independent.

Fifty-eight people, or 40.3%, said they had not undergone an independent assessment as part

of any other scheme. PWDA acknowledges we asked a limited question about people being independently assessed as part of a scheme. We note people with disability have also faced so-called independent assessments in other arenas — such as children's courts, family courts and criminal courts — and our question did not ask about these experiences.

Have you undergone an independent assessment in any other scheme? (e.g. workers compensation, transport/motor or Disability Support Pension schemes)

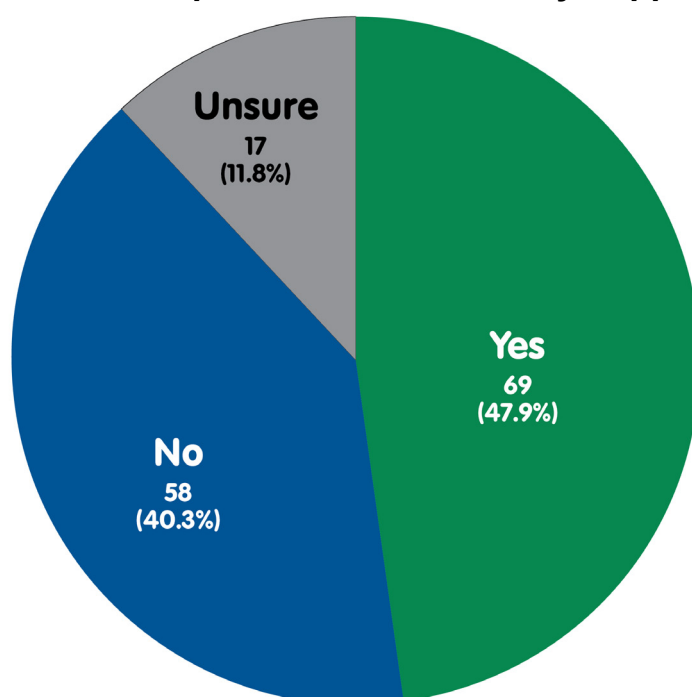


Figure 11 — A large slice of green in a pie chart shows at least 47.9% of people have undergone an independent assessment as part of another scheme or program in the past.

In the next question 77 people identified as going through independent assessment as part of a scheme and named 15 schemes. There were eight additional people identifying as undergoing independent assessment. PWDA notes these eight people could perhaps include people who were not sure if their assessor was independent.

These schemes included worker's compensation regimes, transport or motor vehicle compensation schemes, Centrelink assessments — including Disability Support Pension assessments, the NDIS, income protection insurance schemes and the Blind Pension.

The three schemes most people had undergone independent assessments through were the Disability Support Pension (43 people, or 55.8%), worker's compensation (11 people, or 14.3%) and transport/motor accident compensation (eight people, or 10.4%).

■ If yes, which scheme was the independent assessment part of?

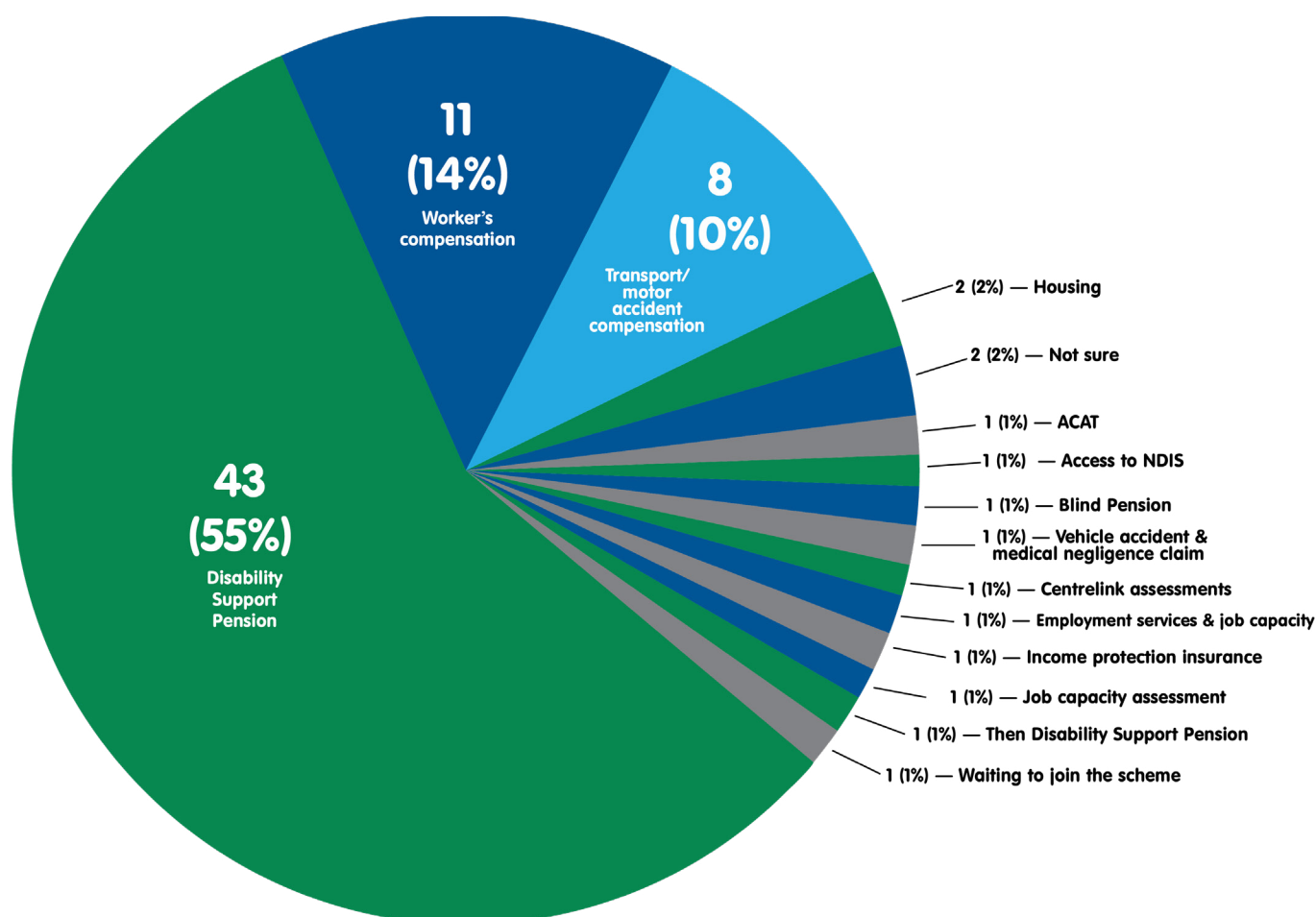


Figure 12 — A large slice of green in a pie chart shows at least 55% of people have undergone an independent assessment as part of Centrelink's Disability Support Pension evaluations.

In this question 85 people identified as going through an independent assessment as part of a scheme and noted their assessment was part of an application, internal review, tribunal or court-based appeal process or a process whose purpose they were unsure about.

Among these people, 44 people, or 51.8%, were going through an application process. Another 13 people, or 15.3%, were undergoing an internal review.

Another 21 people, or 24.7%, were not sure if the assessment was part of an application, internal review or appeals process.

A smaller grouping, of seven people, or 8.2% were going through an appeals process, in either a tribunal or court.

Was the independent assessment for an application, internal review, or an appeal?

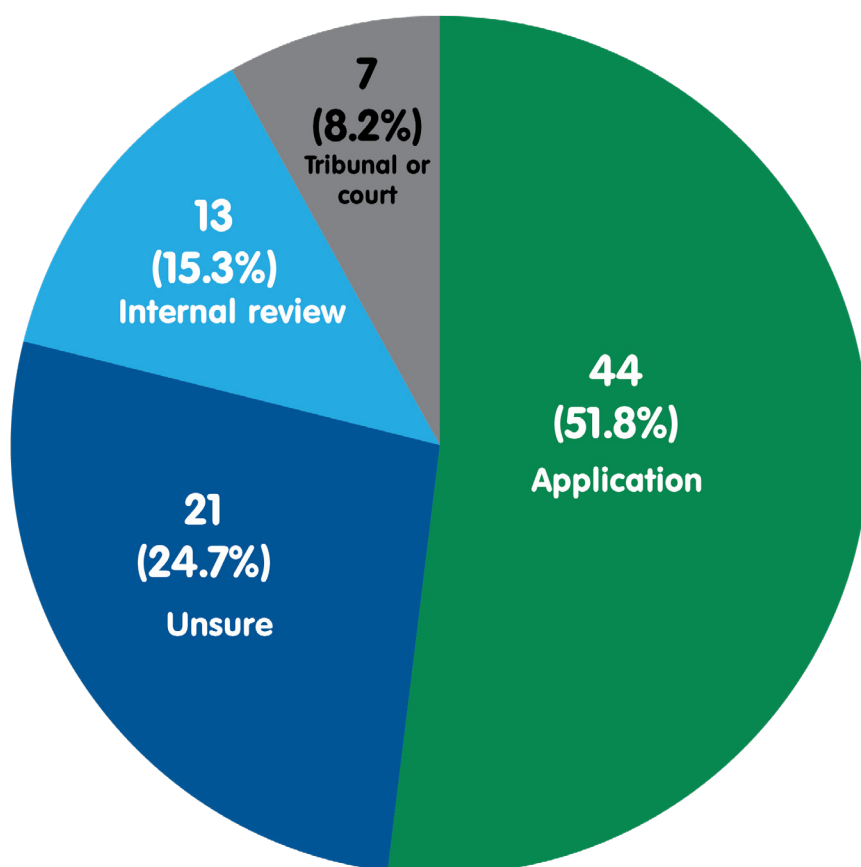


Figure 13 — A large slice of green in a pie chart shows 51.8% of people underwent an independent assessment when applying for a scheme or program.

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- Mensline (24/7) on 1300 789 978.

Sixty-four people who completed the survey, or 43.8%, described their experience of an independent assessment conducted as part of a scheme. Here is what they had to say about their experiences.

Please describe your experience of the independent assessment (i.e. happy, unhappy, was it fair, did you feel heard?) (from 43.8% of people surveyed)

1. It was Inconvenient and difficult to get to but good in the end.
2. I felt heard.
3. It was very bad. The Centrelink branch manager admitted she suspected the assessor did fraud. I had to apply several times because this random contractor didn't care to do good work. No accountability. The event made me suicidal.
4. Too much corruption when the independent assessor also works for the organisation. Level 2 supported accommodation and a housing complaints assessor (Queensland).
5. I felt it was unfair and did not take important factors into account.
6. Waiting, waiting, waiting.
7. Powerless and unheard.
8. Unhappy with the fact that I basically had to put my whole life on the table to prove my disability wasn't going to improve. I had to take my prosthetic leg off to prove I was an amputee.
9. I've had rheumatoid disease for 40 years and have had numerous assessments with government-appointed doctors. I have permanent damage to many joints in my hands and feet which badly affect my mobility. I've had some of these doctors treat me like a liar because I 'look okay to them', especially when I was a younger woman. Even though RA is largely invisible unless one knows what to look for. Depressing when DOCTORS aren't familiar with my condition, especially when their reports can affect my income and life. I've had some male doctors tell me to just 'marry a rich man'! Thankfully I am a good self-advocate but clearly these are instances of unacceptable behaviour and comments.

Recently I've been forced to undergo a medication review with my GP and one other because the rules around opiate-prescribing have changed. They were assessing the treatment prescribed by my specialist rheumatologist! It's ridiculous. I've had chronic pain for decades and without opiates can't function at all. I have NO history of addiction, drug misuse or rehab, no criminal record. Yet, at almost 60 years of age, I am still being subjected to such reviews and though I am a naughty child that can't be trusted to manage my own affairs. Instead on getting a six-month supply from my specialist I now have to see the GP monthly to get my pain meds, at additional needless cost to the system. I am SO over all of it.

10. Again, the interviewer lacked any knowledge of the complex disability and the whole experience was futile. It was humiliating because he spoke to our adult either as a child or did not address him at all, rather addressing the carer.
11. Many opinions when organised by worker's compensation are biased towards the view of WC.
12. Sadly lacking. They wrote things down that were wrong and misconstrued.
13. The lady was lovely but stated that computer did not allow her to enter the information pertinent to make me different to another person with my same primary disability, although as you could see from what I was telling her that I desperately wanted to work, and do when I can, it isn't always possible.

She was correct. She was also correct that the inability of the computer to capture my information accurately meant that I wasn't qualifying for the pension (which I was already mortified to have to be asking for but there are certain times due to my disability only in the last few years that I haven't been able to work).
14. The fear and anxiety of being misunderstood and disbelieved was enormous. It had a long-term effect on me. Despite proving I could not work, they decided I could work 15hrs a week. It was devastating and made my situation a hundred times worse as I could not work.
15. Disempowered.
16. I had no idea what part of my answers they were using to assess me, and I felt completely alienated, and they didn't ask me questions that would uncover my disability and I didn't know how to offer the information.
17. The reviewer had multiple reports and saw me on two occasions! COMCARE.
18. Unhappy, see previous response.

I have had independent assessors paid for by my employer's insurance company assess my situation in a WorkCover case, who failed to accurately take into account the impact of my disability in their recommendations for a safer work environment for me, a mistake immediately obvious to my physio who knows me. How can I be assured this process will not be the same?
19. Happy, they refused me and the assessment ruled in my favour.
20. Could you not describe the LAC as an independent assessment.
21. I felt unheard and disempowered. It focused on highlighting all that I could not do (well). Once they identified tasks I found physically difficult, they then whipped out a stopwatch to time my failures. This allowed them to put a red cross on a graph. Predominant use of closed Yes/No questions led to a cliched limiting understanding of my disability and challenges.
22. Intimidating.
23. Assessor knew little of relevance about my conditions.
24. Report was half-completed prior to interview and assessor was disinterested in speaking with me. They did as instructed by the insurer. I won in court.
25. Seen government doctor after applying for DSP but wasn't until I saw a generalist social worker that my eligibility for the Blind pension was picked-up, assessed and successful advocated for.

26. It was an okay process, but when I got the report under FOI I did not believe that it captured who I was or the complexity of my situation. Been through so many job capacity assessments from Centrelink and none of the reports has been able to even get an elementary understanding of who I was. But equally I am an incredibly complex person with a combination of disabilities including vision impairments, mobility impairments, profound and severe psychosocial disabilities, with an incredibly complex trauma history which I will live in anonymity for life due to it, as intervention orders cannot keep me safe. No one knows what to do with me, if I can be eligible for something does not do anything to improve my quality of life.
27. Unfair the assessor had a pre-examination opinion and simply looked for anything to justify that opinion.
28. Humiliating and demoralising.
29. Extremely ill-informed and not experienced in gathering psychiatric evidence.
30. I felt ridiculed and the lack of empathy had me doubting what I was doing and therefore couldn't get across my feelings properly.
31. Why, you going to exploit us to back NDIS-eligible people when you never advocated for us before?
32. Having been warned ahead of time that this particular medical assessor came down on the side of the insurance company more often than not, I was overwhelmingly surprised that he told the insurance company that I was genuine and managing as well as could be expected given the nature of my injuries.
33. Extremely depressing experience. Felt violated and like an object. Did not feel human.
34. Are you just assuming that people who respond to this are NDIS participants? Don't forget that 90% of us are not and won't be. PWDA is misnamed. It is not Australian, just about NSW or Sydney really. And it is not for all people with disability, mostly just for NDIS participants.
35. The Centrelink psychologist nodded off three times.

The interview was long very taxing on me. The questions were invasive and personally offensive and inappropriate. Most should have been asked by a doctor. The doctor stated if my conditions weren't in the medical reports he wouldn't support me. He stated he wasn't going to give me drugs, examine me and didn't ask me any questions.
36. Was hard due to extreme fatigue getting there and sitting there for an hour but the doctor was local, knew my specialist was one of best-in-country, and was really decent.
37. It made me feel extremely anxious, but the assessor seemed very fair.
38. Fair. Effective as an assessment, hopeless in terms of care provision as the local assistance is very under-resourced.
39. Indifferent.
40. They seemed disinterested.
41. I felt like the assessor was on the side of TAC and looking for reasons to downplay my injuries.
42. Clinician report was inaccurate, and despite registering many aspects of my subsequently diagnosed disability, failed to accurately diagnose it.
43. Very unhappy how family have been treated.

44. Based on my written application for DSP, and NDIS, I was denied both times, the support I needed, and then on review, both the Commonwealth Doctor and the Senior NDIS Planner, apologised for the total lack of understanding of my needs and the support I required. The NDIS apologised “for previous plans being grossly underfunded”, as did the C’With Dr.
45. I was treated like a CATEGORY not an individual person who has now seen both sides of a disability fence!
46. It was onerous, lacked clarity, was designed to make people fail, because questions are framed for eliciting particular responses and don’t take into account the many variables that occur from human to human.
47. We had no choice, that was the system, it was lucky we had a professional and emphatic assessor.
48. The issue is the person is housebound and cannot attend face-to-face appointments. The first assessment, JCA, was done via file assessment, but the next DMAS was to be done face-to-face — it took months and months for them to think about how they would do this assessment. As a result, the DMAS was done over the phone with the POA as the person cannot use phones due to psychosocial and trauma disabilities.
49. Happy.
50. My experience was traumatising — most didn’t listen and didn’t care and wrote a pack of lies. Two assessments were fairly and honestly conducted.
51. Mine was fair two-to-one, but one Dr said my brain damage was not real when the PET scan images and report in his bundle showed otherwise.
52. I thought it was a waste of time. They already had all of my medical records from my multi-disciplinary team, how can a regular GP assess me when other more qualified medical professionals had already done so. I sat through pain having to travel, went through further unnecessary pain during the examination and questions. It was a very painful waste of my time and the GP’s time.
53. Thankfully I had gathered enough evidence over the two-and-a-half years it took me to get in the DSP that it wasn’t looking like I’d be rejected so it worked out for me, but if I hadn’t spent that time and money on it I know I would not have passed it. I still felt like having a GP I’d never met assess a very complex part of my life in order to make a decision that would affect my ability to survive was a cold and unfair approach to addressing my needs.
54. I was humiliated by the assessor’s approach telling me I should never have children. It was many years ago and yet it’s as clear as yesterday.
55. I felt relieved that, after battling for years with clerical workers in Centrelink offices, I had an opportunity to discuss my issues with a medical professional.
56. This independent assessment was done in early 2013. It wasn’t until I applied for NDIS and then finding out what this assessor had evaluated with NO knowledge of Mitochondrial Diseases and its numerous variants, that my lack of support for physical needs was enlightened.

Because Mitochondrial Diseases wasn’t listed part of their (Dept. of Human Services) input in their software, the assessor obviously just chose whatever she thought might fit a slot. I was not treated as an individual with individual challenges and needs, instead she (assessor) thought with her ignorant knowledge to actually, in my opinion, to make things simpler for her job, lied and because of my Ptosis condition due to chronic progressive

Content warning: a number of people with disability shared they felt suicidal when thinking about independent assessments and were extended support by PWDA. If you have suicidal thoughts, you can call:

- Lifeline (24/7) on 13 11 14.
- Suicide Callback Services (24/7) on 1300 659 467.
- Mensline (24/7) on 1300 789 978.

external ophthalmoplegia and Kearns-Sayre, she noted that I was clinically blind. I am not Clinically blind. I have CPEO and Kearns-Sayre which affects my whole body. Every cell!

When I was treated strangely by the very few and immensely inadequate supports I was given, I questioned many of the controlling bodies regarding my case and was always treated poorly with replies that they weren't allowed to tell me what was on MY assessment.

57. I was accepted onto the program but was not given the resources or tools for sustained support.
58. Terrifying!
59. The assessor didn't ask about my disability at all and made up a number of statements in their report, based on their own assumptions, which were wrong — every person is different and affected differently by their disability and by trauma. I wasn't heard and I was subjected to multiple annual assessments even years after initial assessments.
This became extremely traumatic and I have never forgotten it nor got over it. The assessors are from big companies without a hippocratic oath ethic. They are simply about getting big money from the assessments and don't care about the impact on the person, even if it destroys the person psychologically or loses them their income or home. The assessments have become an industry with their own agenda of treating persons with disabilities as cash cows. It is unbalanced because the participant's own medical practitioners get paid a fraction of the amount under Medicare or in the case of psychiatrists, the participant is out of pocket since it is rare to find a specialist who will bulk-bill. The NDIS would be better served by paying for the ongoing medical care and getting a report from the treating practitioners.
60. I felt that I was under very harsh scrutiny and felt like I was acting all wrong.
61. I am a Clinical Psychologist and I have had ample opportunity to see the damage caused by independent assessors in the MVA and workers compensation scheme.
62. It made me so anxious about my future that I had a mental breakdown with suicide idealisation.
63. They had no experience in my disabilities. It was pointless and most of it was spent trying to educate the assessor.
64. My disability is obvious, it was a no-brainer.

Question 6 — What would you like the government to do about independent assessments?

Thirty-seven people, or 25.5%, said the Australian Government should not go ahead with independent assessments for the National Disability Insurance Scheme.

A 145-person majority answered PWDA's question **What would you like the government to do about independent assessments?**

Thirty-seven people, or 25.5%, said the Australian Government should not go ahead with independent assessments for the National Disability Insurance Scheme.

A further 67 people, or 46.2%, said let people choose whether they use an independent assessor or their own health professional.

Three people, or 2.1%, believed there should be more pilots or trials of independent assessments.

Twenty-three people, or 15.9%, thought the government should go ahead with independent assessments for the NDIS.

One person said they believed assessments should be delivered by a provider and assigned a Medicare item number "so there is clear distance between the assessor and the NDIA and we can go to a therapist et cetera with specialist knowledge of our conditions."

■ What would you like the government to do about independent assessments?

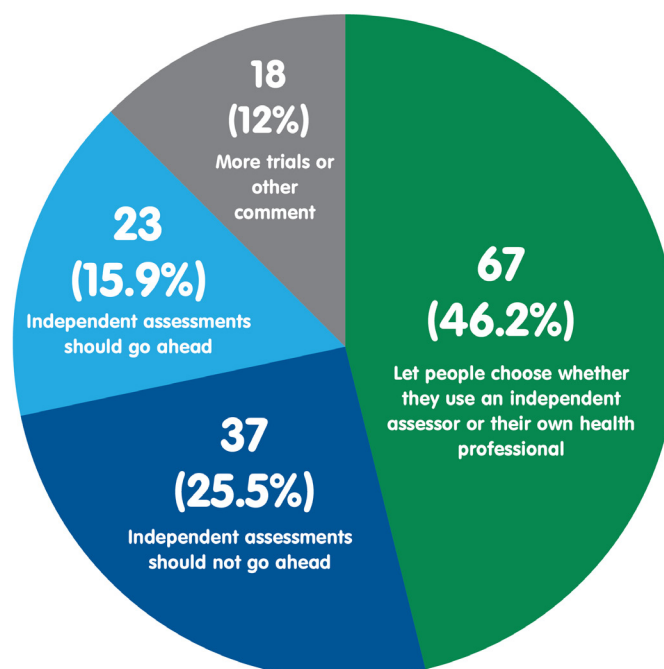


Figure 14 — A large slice of green in a pie chart shows 46.2% of people want to be able to choose an independent assessor or their own health professional.

■ Other comments:

1. Go ahead with independent assessments but ask people with disability how it should work.
2. Don't go ahead but pay for all assessments required for the NDIS (including for Access) and provide assistance with finding assessors if the participant wants this.
3. Have more pilots/trials of independent assessments.
4. Go ahead with independent assessments, but only for access applications (and not plan reviews).
5. Ideally *Not go ahead with independent assessments* However if there must be a compromise, let people choose whether they use an independent assessor or their own health professional.
6. Go ahead with independent assessments but ask people with disability how they should work.
7. Go ahead with independent assessments, but only for access applications (and not plan reviews).
8. Answers 3, 5 and 7.
9. Let people choose an independent assessor for their own health professional. And then don't take the funding out of the person's plan because it is the NDIA requesting the report. That will avoid entire new plan, something to be written up just to allocate the funds to pay for the assessment. If this change is not made it is pushing people to choose an independent assessment but they may have preferred to use their own assessor if they don't have sufficient budgeted funding remaining in their plan for a report which is suddenly requested (most of us know how many times we need to see our allied health professional during the year and budget accordingly so a request for an extra report won't necessarily be within our budget).
10. Let people choose any provider they like and have NDIS pay for the assessment, just like how NDIS pays for PPE at the moment not out of plan money.
11. See what each person needs.
12. See response to first question.
13. Only use independent assessments when an individual does not have their own medical professional to provide the required evidence or cannot afford the associated expense.
14. Concentrate on simplifying the plan review and access process by eliminating the LAC role, providing more intense training for Planners and allowing participants to view their proposed plan before it is approved by a planner.
15. Start again .. there is no clear indicator they are better than current process, which is already bad.
16. Make the assessment (for access only) a Medicare item so there is clear distance between the assessor and the NDIA and we can go to a therapist etc with specialist knowledge of our conditions.
17. They need to factor in their track record with the AAT re: IAs and they have not had a great success rate and their IA assessors have been shown to be delivering poor assessments but they don't care because they get bonuses. There is no independent assessment because these people are employed by the NDIA and they receive bonuses. The AAT has shown these assessors are doing anything they can to reduce funding or access to the scheme, I wouldn't be surprised that for every \$1K they save the government, they get it themselves.

Question 7 — Would you like more information from the government about independent assessments?

Our members laid out specifics things they wanted the Australian Government to tell them about independent assessments

Fifty-eight of the 146 people who completed PWDA's survey, or 39.7%, answered the question **Would you like more information from the government about independent assessments?**

Fifty-three of the 146 people who completed PWDA's survey, or 36.3%, indicated they would like to know more by answering the follow-up question **If so, what would you like to know?**

Our members laid out specifics things they wanted the Australian Government to tell them about independent assessments and these things are outlined below.

Five people, or 3.4%, said no they did not want more information from the government. Only one person gave a reason, saying they believed "The government just tells us lies."

Another 88 people, or 60.2% of those surveyed, had no further questions or comments.

If you would you like more information from the government about independent assessments, what would you like to know? (questions from 36.3% of people surveyed)

1. I'd like them to stop. It's hard enough to live with the medical PTSD that gaslighting caused me over a lifetime of living with a rare disease. I don't need any more trauma.
2. How much they will cost and how will they work, what is the process.
3. Why are they trying to hurt us, we didn't do anything wrong.
4. Who voted for them and why. Who they listened to in the disability community.
5. Yes, when will they pilot just physical disability — what about comorbidities and multiple disabilities?
6. Why are treating doctors and specialists not considered the experts in determining their long-term patients' needs? 'Independent assessments' seem to me to imply that doctors and patients are in cahoots in trying to rort the system. It's offensive and infantilising.
7. How will the assessors be screened for knowledge of particular disabilities? Often families and the people themselves have more knowledge than therapists.
8. Why do they not trust our own medical personnel? Why do they treat us as liars and manipulators? Why put us through such humiliating and detrimental experiences such as these assessments?
9. I don't trust the government.

10. Yes — full details of the first pilot program and a detailed commitment to consultation with many different communities of persons with disability. Particularly persons with disability who are Aboriginal, Torres Strait Islander, transgender and gender diverse, who come from Culturally and Linguistically Diverse backgrounds, who do not use verbal language, and/or have significant cognitive and intellectual disabilities and their informal supporters, all of whom are likely to face significant issues and disadvantage due to the Independent Assessment process and its lack of choice over culturally appropriate, safe, and well-trained service providers.
11. Where is the Choice and Control? Where is OUR voice? This is the worst kind of patronising against people with a disability.
12. Will the assessments paid for by the NDIS be the only thing that determines eligibility for the NDIS and my ongoing access? How can I be assured my evidence will be given primary consideration over a potentially misguided independent assessment?
13. How is the chosen professional going to assess me, when my body works differently at a cellular level due to the nature of my disability? Most doctors I see don't even know how my body can do the weird things it does!!!
14. Why they want to do this.
15. Why do we not have someone that is local in your area that you can talk to face-to-face.
16. I have read the government info. Not impressed by the concept, nor its utilisation or the 'transparency' of the reasoning behind its introduction.
17. Why it's good? Why it's different?
18. Information more widely provided, including sending postals (received mine as email) to make disabled people more aware and informative of the process.
19. Yes — are general accredited and non-accredited social workers being considered in all this — 'once bitten twice shy' as they say.
20. Easy Read resources.
21. What exactly is involved and why it is necessary to have it.
22. There needs to be much more thought about this, more trials and careful wording of legislation — need to be able to appeal them, need more safeguards around them. Equally need to look at the person's whole life, not just the NDIA.
23. I would like to know how the independent assessors are chosen, criteria and qualifications.
24. To be explained more.
25. More clarification of how exactly independent assessments will work and under what circumstances they will be used. More transparency. Currently comes across as a means to find reasons to deny services.
26. If the health professional already assessed and dingos, any doubt for health professionals. Then we can't trust them any more for treatments.
27. Yes. To date the NDIA have shown they don't understand the difference between diagnosis, impairment and disability, and their policies often conflict with the NDIS Act, which is actually pretty good and clear. The outsourcing of these assessments is a mistake and will cost everyone. It should be done and could be done well, but I have no confidence that it will be.

28. Yes, I want to know how any assessment will deliver any outcomes and by when? If none delivered, then why bother starting the assessments.
29. Yes. What is the real reason for them and why they think that my disability isn't real.
30. Just don't do it.
31. Who exactly will do assessments, what incentive do they have to reject you (as now they obviously are instructed to reject you, as in DSP applications, as shown by FOI applications for assessment/application records) and will it be customised to every person's circumstance.
32. As much information as available.
33. Why????
34. It should only be independently assessed when there is lack of services to support the individual — i.e. in regional areas, for example.
35. Everything! How are assessments done, compiled and logged?
36. I want it to be optional.
37. How it will work. Who will be doing the assessments?
38. Who will carry out the assessment? The assessor will come from which profession? Will we be given their qualifications?
39. I want an answer as to how it can possibly be considered independent because they are employed by the NDIA/government for a start, I want to know how much in bonuses they are getting (and they are, I know of professionals who have been contacted to do the role and are being offered bonuses) and what they are getting the bonuses for. I want to know what the KPIs are (all, not just the ones issued to the public) for the IAs. How can they state that these are successful, as the website information has purposely been written to defraud the population (only 28% of surveys completed and only a small percentage stated they were happy). I want to know if their processes and procedures of this are covered under the APS Code of Conduct and if someone wants to complain, how can they complain independently of the NDIA as a person recently complained and it went directly back to that person even though they did the wrong thing and have clouded the response.
40. A transparent and honest understanding of the processes involved, criteria and outcomes.
41. Why are they going down this path?
42. How is the process independent when it is being paid for by the insurer?
43. Has the government or NDIA assessed the kinds of people who have fallen through the cracks of this scheme? When people decline to be involved in the pilot do they have the chance to provide feedback as to why, and is that factored into whether they're reaching the people they need to?
44. When they plan to scrap them.
45. Yes. Safeguards and appeal mechanisms.
46. The process, who would be doing assessments, if there is an option to have another independent assessment by someone else if you think the first one was wrong or if it goes straight to appeals process, specifics on how this will work for those with psychosocial/ neurodivergence (since they are identified as particularly at risk in this scenario).

- 47. I would like to know why the government wants to potentially waste more of our taxpayers' moneys to make ignorant decisions regarding people's lives.
- 48. Why they won't provide report/outcome to participant.
- 49. I would like a detailed point-by-point description of the process and why it is being used as opposed to the treating practitioner's assessment.
- 50. If it is mandatory.
- 51. Yes.
- 52. Release the full pilot report, release both documents listed in the framework that are internal documents only.
- 53. What business do able-bodied people have in determining disability? The government gives in one hand and takes on the other. White-collar administration has no idea of the daily difficulties suffered by people with disability. Government should be scrutinising politicians' wages and pensions, not disability.

Question 8 — Do you have any other comments about independent assessments?

Sixty-two of the 146 people who completed PWDA's survey, or 42.5%, answered the question **Do you have any other comments about independent assessments?**

Fifty-five people, or 37.7%, of the survey had other comments. These are laid out below.

Four people, or 2.7%, said they did not have any other comments. Another 84 people, or 57.5% of those surveyed, gave no extra comments. The total number of people not making additional comments was 88 people, or 60.2% of the survey.

Do you have any other comments about independent assessments? (comments from 37.7% of people surveyed)

1. It will be interesting to see how the LNP can get another Rory happening out of this one.
2. Yes, I hope it costs them the next election and we can actually breathe a little for a whilst instead of living in constant fear of poverty and homelessness.
3. Providing explanation about your disability to a new person every time.
4. Don't rush through until more people know about.
5. The reports say that the trial was discontinued. It's not really a relevant comparison to their proposal because it was an opt-in situation. What they are proposing is mandatory.

If the trial was discontinued it would have no validity as empirical evidence and any analysis would be highly inaccurate. To use that as their evidence base would be utterly dishonest and extremely questionable practice.

If there is statistical quantitative analysis and a peer-reviewed report, there would be a "p" value. That is an indicator of its reliability as research. Do we have a p-value?? Do we even have a peer-reviewed report?
6. If you want to do stuff like this the system needs to change, society needs to change, inclusion and discrimination needs to change. As a society we still have a long way to go.

A question for the ministers making this decision — are you happy to tell me what your goals and wants are for the next 12 months because I would be happy to swap your life for mine and see what you think of living on not-much and paying for things that others don't need, to just live, and having to justify your life and actions.
7. Whoever designed this plan clearly has no respect for disabled people or their doctors. We know what is best for us, and our doctors know us, our circumstances and needs far better than can be determined by one visit with a stranger.
8. They will be less efficient, more open to mistakes, more costly because of those mistakes and the program denies the expertise of therapists who are familiar now with their clients.
9. They should not exist, it's wrong and a horrendous thing to be facing.
10. I am not in favour of independent assessments. They need to be done by health professionals who have worked with them for a period of time.

11. NDIS needs to fund reports by professionals chosen by the participant/prospective participant.
12. IF people choose to have these .. they must have other reports from OTs and Physios et cetera. And these reports must be used.
13. I dread having to go through this new process at plan review. My life in the healthcare system has left me incredibly distrustful of health professionals I don't know. The proposal to involve independent assessors honestly leaves me feeling quite scared.
14. Seeing a lot of whinging from well-off already-diagnosed straight white people in well-serviced metropolitan areas... Just saying.
15. Show us what the criteria is for assessment that the people will be working to.
16. Hopefully independent assessments are wholly independent as the name implies which would give confidence of being heard and assisted accordingly.
17. It's a slippery slope.
18. Empower general and accredited general social workers easier access to the system, as we are accountable to colleagues and risk losing this should complaints be lodged. We have been locked out, despite assurance to the contrary.
19. It is a good idea to have the ability to fund assessments available, particularly for access, for those who cannot afford a private assessment prior to accessing the scheme and do not already have a relationship with an appropriate health professional, but this is not the way to do that.
20. They definitely concern me and I think that NDIS participants already supply enough medical evidence.
21. Just stop them. This is a bad idea.
22. Independent assessments work to enable insurers to achieve their own goal.
23. Should not apply under any circumstances to people already admitted into the scheme unless there is undeniable evidence that a person's condition is being grossly exaggerated to gain greater benefit.
24. Make Independent assessments around intelligence and psychopathy for politicians mandatory so they cannot remain in parliament if they do not make the grade for a reasonable human being.
25. Independent assessor doesn't know my condition as my health professional does.
26. We should be most concerned about this being outsourced from the NDIA. That won't work, as we have seen with LACS. There has been too much emphasis on the assessment tools instead of the governance and process. Independent assessments are important and should always have been part of the NDIS. The public outcry is unwarranted and shows a lack of understanding of the Scheme. The real problem is "how" it has and will be done; the quality and fairness.
27. Yes they need to stop telling how my disability affects me. If they have to do this ask me the questions and believe when I make a statement. Don't keep going to everybody that works with me or is related to me whether or not I'm telling the truth or verification of what I say.
28. It's a terrible idea and utterly insulting to persons with disability and their own health professionals, many of whom they may have been working with for years.
29. They should ideally assess you in your home if requested, to see how you live.

30. I am about to apply to the NDIS, so would have appreciated the option to say not applicable or something similar.
31. I do think the assessments may be helpful, but the length of time is far too long. As I've already said, for me personally, that period of time would leave me very unwell for a number of days.
32. How about sending PWDA members information regarding this subject before filling in a survey???
33. Is this another cost-cutting exercise??
34. Just the thought implies individuals do not know what they need, when we are the most informed to make those decisions — we need support not further assessments in our lives!
35. Proof of positive outcomes will be in the eyes of the client NOT the assessor or the public service which seems to be blinded by legislation that is outdated and inadequate!
36. If someone has qualified for a disability pension, then they should arguably be automatically qualified for admission to NDIS. They should ALWAYS have the right to provide assessments or reports prepared by the health professionals of their own choice, in accordance with the stated aim of the scheme.

If we're talking about the ability to pay for these...each applicant can be initially funded to have reports prepared since there is an initial application process to go through.
37. They are not independent, they will be paid by the NDIA.
38. Can we please stop calling them independent assessments as they are not independent in any shape of the word.
39. They must not be mandatory. End of.
40. This is obviously a way for the government to cut back on funding and services for people with a disability and reduce the number of people that access this scheme and reduce the level of funding to those in the scheme.
41. How does this impact us against the UN convention in the area of disability rights.
42. They suck green monkey balls.
43. See answer to question 2.
44. Last week I sent the NDIS assessments email address a list of questions I have before I agree to participate in their pilot and they haven't acknowledged my email at all. This is delaying my ability to get my wheelchair, which is four years past when I first needed it, and it's causing my health to deteriorate rapidly. I'm extremely frustrated with this process already and I haven't even been able to confirm my involvement yet.
45. This will set the NDIA back so far, it is the opposite of everything we fought for and feels like a way to cut costs, not give us equality.
46. I see it as a further attempt by this government to minimise the number of claims.
47. Who are going to be the independent assessors and, if they don't already work in the disability sector, how would they have the skills and experience to assess potential and actual participants?
48. I don't think the current system is beneficial to participants, only to the myriad of providers who have emerged like mushrooms after a storm!

49. I'm really afraid of losing the support I've needed for almost my entire life and have only had for a year-and-a-half because the fact that I am articulate and self-aware is almost always used to deny me support.
50. Implementing independent assessors assessing without choice to the individual is totally against what NDIS is about — the right to individual choice.
- To make independent-assessing mandatory would be going back to an old system that didn't work and had way too many flaws that, in my opinion, did not serve people with disabilities with fairness and respect.
- The buzz word 'inclusion', which I personally dislike immensely, to include people with a disability to be part of 'normal society', is missing from the choice we, as people with disabilities, have to have a 'normal' life and be included in society to have our own choice and voices heard.
- BTW. I prefer 'equal' to 'inclusive'. Dictionary-meaning inclusive: including all the services or items normally expected or required. Wow! Thanks for the invitation! When and where is one person's life more valuable than the others?
51. It violates human rights that all are entitled to.
- Invasion of privacy by a complete stranger.
- Assessment should be used by choice to adjunct person's application to NDIS not as a qualifying measure. Therefore it should not be used by NDIS to use on already existing participant.
52. 1. Make the entire assessment form and scoring public.
2. Allow the participant to provide a score (themselves or carer) and where there is significant variation ask participant for evidence.
53. If they go ahead, then they should be at the participant's choice of whether they have one or not, and whether it is by their own treating practitioner or an assessor who knows very little about the participant and only goes off paperwork and a short in person appointment to come to their conclusions. The participant should be allowed to have it in their home if they choose, where the impact of the disability can be more visible — like the plan reviews. They should also be allowed as many support persons as they feel the need for — like at plan reviews.
54. We need more people with disabilities on the NDIA Board and other decision-making committees. Whatever happened to "nothing about us, without us"?
55. I would prefer to choose whether to have an independent assessment, but if the government thinks this would just cause inequality between participants then I guess I would have to do it.
56. I worked for the federal government as a mental health professional in the Disability Sector since the 1990s, until my retirement in 2010. Prior to my retirement from the public service in 2010, for the last ten years I was a Senior Psychologist employed by Centrelink to lead a team of allied health professionals/assessors. The use of standardised programs to do assessments, ultimately turns into process work. Since retirement from the public service, I have continued working in private practice as a Clinical and Health Psychologist. During this period I have also applied and was offered work as an independent assessor associated with Disability Support Pension. However, I was so discouraged by the restrictive assessment practices, that I only did it for a couple of months. This type of work is not attractive, long-term, to most professionals, and you end up only with people who

are happy with doing “tick-and-flick” assessments. I continue working in private practice with a special interest in working with clients with chronic medical conditions and disability. As such, I feel well qualified and able to provide true assessment of clients’ capacities and needs. Clients’ own health professionals are much better qualified to provide quality assessments than independent assessors. My response does not reflect any concern about potentially losing work if independent assessors were used, because I do not charge my clients to provide assessment reports, and I am intending to permanently retire very soon. I have seen the damage done by independent assessors, and I, personally, would certainly not like to be assessed by anyone other than my own health professionals.

57. The pilots were poorly designed and implemented. The sample was not representative, there’s been no transparency, and they weren’t even planned as a way of consulting us, they were planned for assessing the agency use of the tools they had chosen.
58. Refer to my other answers.

Question 9 — What are your demographics?

Of the 146 people who completed PWDA's survey on independent assessments, 142 people, or 97.3%, chose to name a gender they associate with.

Eight-two people, or 57.8% of those willing to talk about or describe their gender, said they were female, while one more person said she was a mother-of-three. People who were willing to identify as a woman therefore made up 58.5% of the survey.

Forty-three people described themselves as male, representing 30.3% of the people who talked about gender.

A further eight people, or 5.6% of people answering this question, said they preferred not to say their gender.

Another nine people, or 6.3% of respondents on this question, described their gender in a variety of ways, including non-binary, fluid, transgender and gender diverse.

■ Gender breakdown of survey participants

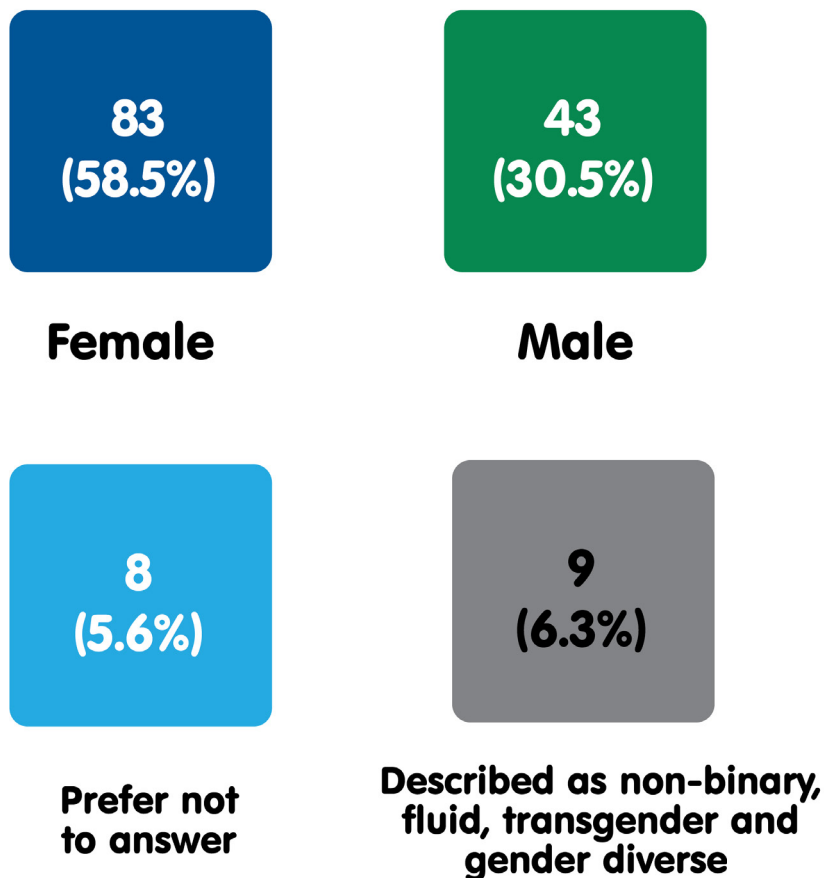


Figure 15 — A dark blue square in the top left of the chart shows 58.5% of the survey identified as female, while a green square in the top right shows 30.5% identified as male.

One hundred and forty-five, or 99.3% of the people completing PWDA's survey, flagged which age range they are in.

Eleven people, or 7.6% of the people completing this question, were in the 18-to-30-years age range.

Twenty-five, or 17.2% of people describing their age, were in the 31–40 age range.

Thirty-seven, or 25.5%, were in the 41–50 age range.

Forty-five, or 31.0%, were in the 51–60 age range, making up the biggest group in the survey.

Another 26 people, or 17.9% were aged 61–70, while one person (0.7%) was 70-plus.

■ Age breakdown of survey participants

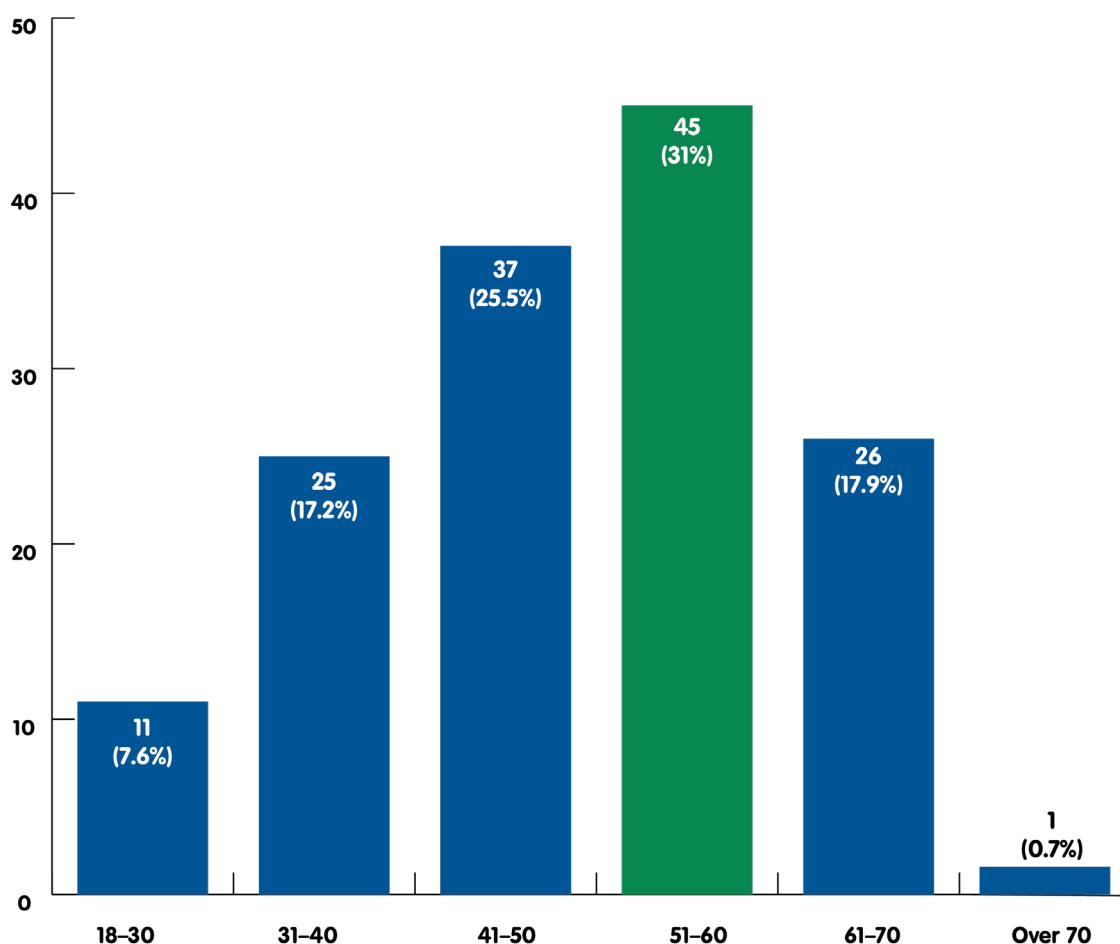


Figure 16 — The tallest column in a column chart shows 31%, or the biggest group of people doing the survey, were aged 51–60 years.

The 146 people who completed PWDA's survey came from every state and territory in Australia. One hundred and forty-five of those people, or 99.3% of those people chose to tell us which state and territory they lived in.

The biggest grouping of people was from New South Wales, with 50 people, or 34.5% of people answering the question identifying as living in the state.

Thirty-five people, or 24.1%, were living in Queensland.

Thirty-two people, or 22.1%, were based in Victoria.

Eleven people, or 7.6%, were from Western Australia.

Seven people, or 4.8%, were in South Australia.

Six people, or 4.1%, were living in Tasmania.

Three people, or 2.1% were from the Australian Capital Territory.

One person, or 0.7%, was in the Northern Territory.

■ Geographic breakdown of survey participants

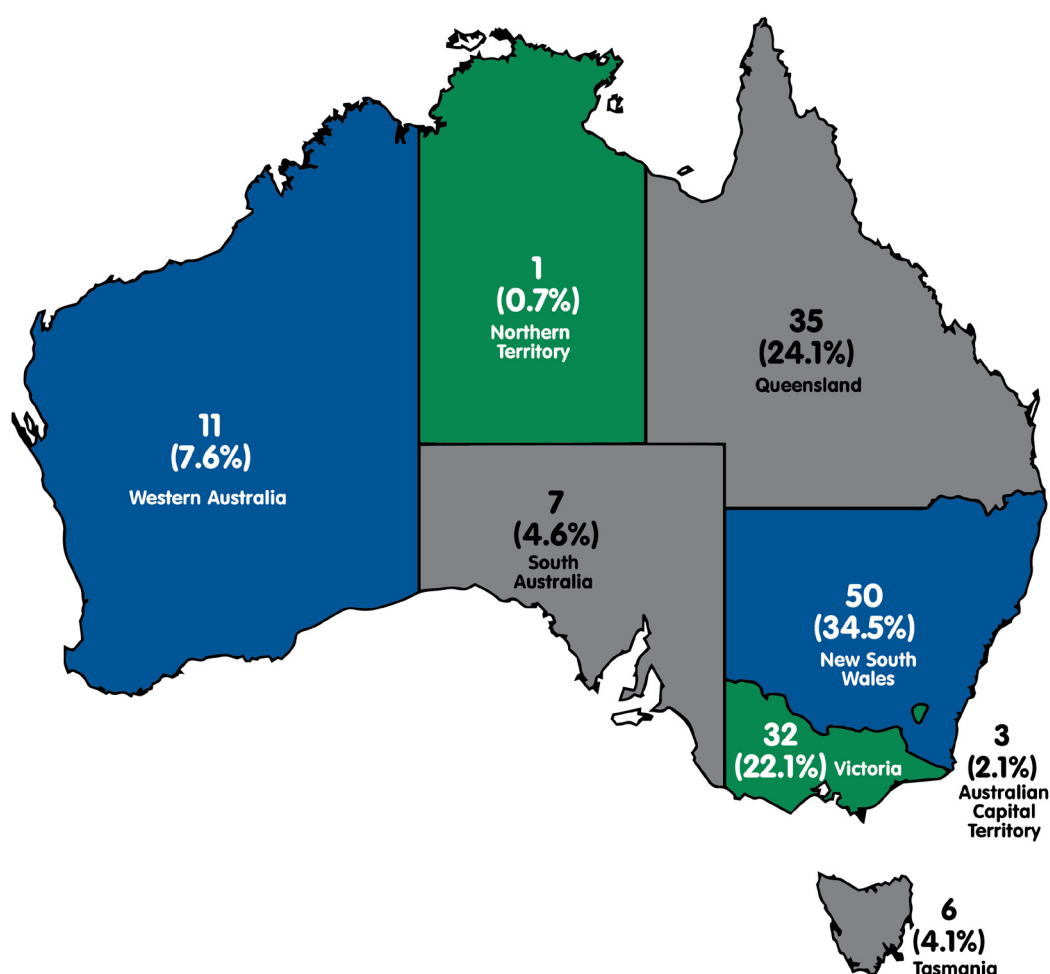


Figure 17 — The dark blue-shaded state of New South Wales, in a map of Australia, shows 34.5%, or the biggest group in the survey were from the eastern state.

One hundred and forty-four of the 146 people who completed PWDA's survey, or 98.6%, told us if they were based in metropolitan or rural-remote areas.

Ninety-one people, or 63.2% of people answering this question, were based in metropolitan areas.

Another 53 people, or 36.8%, said they were based in rural or remote areas.

■ Metropolitan and rural breakdown of survey participants

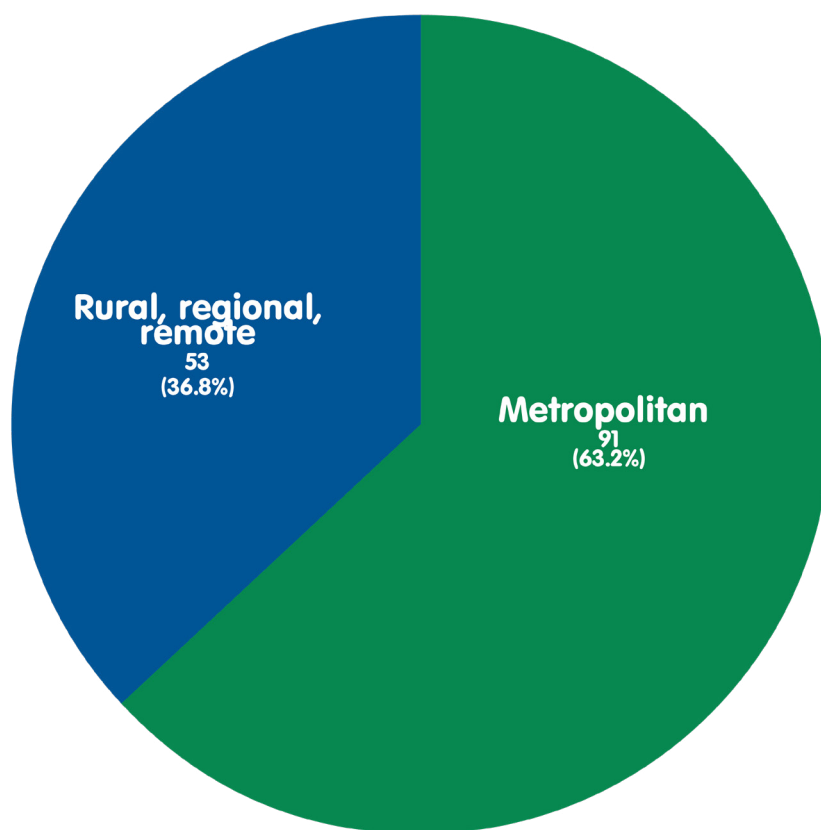


Figure 18 — A large green slice that takes up more than half a pie chart shows 63.2% of people doing the survey were from metropolitan areas.

One hundred and forty-four of the 146 people who completed PWDA's survey, or 99.3%, described their status with the National Disability Insurance Scheme for us.

One hundred and two people, or 70.3%, were NDIS participants.

Another 27 people, or 18.6%, were applying for the NDIS or planned to in the near future.

Therefore, 88.9% were people who could take part in independent assessments if they are introduced in the next year.

Sixteen people, or 11%, were not NDIS participants and did not plan to apply for the NDIS in the near future.

■ NDIS status breakdown of survey participants

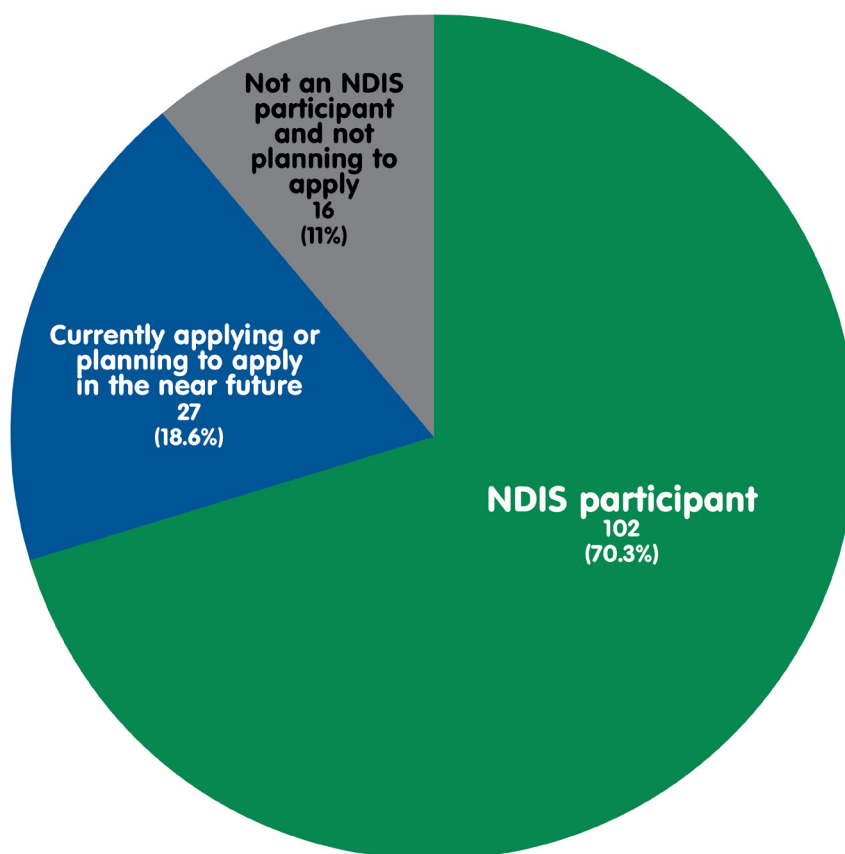


Figure 19 — A large green slice that takes up more than half a pie chart shows 70.3% of people doing the survey were NDIS participants. A dark blue slice of the pie shows 18.6% are planning to apply for the NDIS in the near future.

All 102 of the people in PWDA's survey who told us they were NDIS participants answered the question, If you are an NDIS participant, how many plan reviews have you had?

Nine people, or 8.8% of people flagging they were NDIS participants, had undergone no reviews.

Nineteen people, or 18.6%, had taken part in one review.

Sixteen people, or 15.6%, had had two reviews, while another person (1.0%) said they had undergone "a few" reviews.

Twenty-seven, or 26.5%, had undergone three reviews.

Twelve, or 11.7%, had experienced four reviews. One of these people told us they had also undergone a RORD assessment, while another said they had also had a decision review.

Five people, or 4.9%, had undergone five reviews.

One person, or 1.0%, had had six reviews.

Two people, or 2.0%, had experienced seven reviews.

One person, or 1.0%, had lived through 11 reviews.

Another person, or 1.0%, had the most number of reviews they had personally experienced, being 12.

A mother and carer of several children had undergone 14 reviews. She represented 1.0% of people answering this question.

Two people (2.0%) said they could not remember how many reviews they had undergone, while another person (1.0%) said they had experienced many reviews. A third person (1.0%) said they had had multiple reviews.

■ If you are an NDIS participant, how many plan reviews have you had?

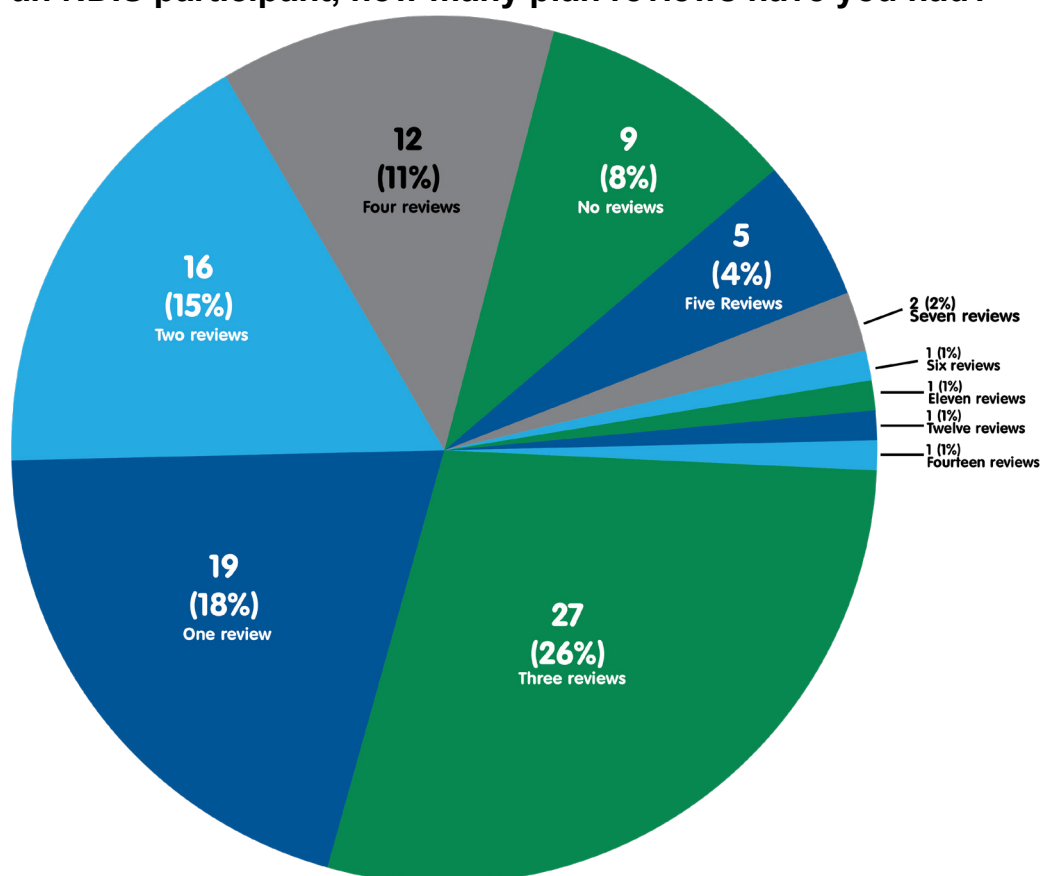


Figure 20 — A large green slice that takes up more than a quarter of a pie chart shows 26%, or the biggest group of people doing the survey, had undergone three NDIS reviews.

Question 10 — Is there anything else you want to tell us about your experiences with the NDIS?

A 63.7% majority of our survey outlined their experiences with the NDIS

Ninety-five of the 146 people, or 65.1% who completed PWDA's survey answered the question, **Is there anything else you want to tell us about your experiences with the NDIS?**

Ninety-three, or 63.7%, of our survey highlighted their experiences with the National Disability Insurance Scheme.

Another two people, or 1.4%, said they did not want to tell us about their experiences with the NDIS. A further 55 people, or 37.7%, stayed silent. All in all, 57 people, or 39.0% opted to keep mum on their experiences with the NDIS.

Here are our members final words on their experiences with the NDIS.

1. It's good but the process and bureaucracy kills me.
2. It's a nightmare to navigate as it is. We don't need any more one-size-fits-all privatising!
3. The system needs to be better and does not allow choice voice and control in every category as it is supposed to.
4. I am the parent of a deceased child who had one poor plan, one review due to appeal, and then an extension of the same poor plan for the last three months before she died. I have not had a plan nor do I intend to apply in the short to medium term.
5. Mindful of info, sometimes an overload, but very happy with scheme.
6. I hate how they keep changing my LAC, every time I finally get a good one they leave within a couple of months.
7. I was on NDIS. It ended up costing me more money. Two years back on old funding package and I am still paying professionals back. So a big fat never ever again from me. I am also watching two friends go through hell with NDIS and providers.
8. I have applied and been rejected, it is extremely difficult to receive approval without an advocate's assistance. This should not be such a difficult process.
9. I had to go to AAT to gain access and some of the NDIS employees I dealt with were extremely rude and dismissive.
10. I feel like there's a black thunder cloud always following me — plan reviews are a terrifying experience.
11. The system needs change and work, and more involvement from those who have a proper understanding.
12. Overall it has been a very good experience giving greater independence and choice. Having independent assessors is a backward step.
13. Not available to people over 65.

14. Very little help around.
15. From what I have observed, extra resources should be allocated to the planner having more time to read thoroughly and think about the information they have just learned from you and write your plan on the spot rather than having to move onto the next meeting, the next meeting and pump out plans. It is this which has led to so many memories in the case of myself and many of my friends, all of the information is written there in reports and the planner apologises when we have to launch appeal or review. It's simply been accidentally not copied and pasted or overlooked or misunderstood in the haste to get the plan done and move onto the next one. Be able to make a slight change when there's been a plan — or leaving a default is agency-managed to plan or self-managed without that during a review — and in time new plan start and end date, which causes a new service agreement with surprise and, in my case choose up Support Worker hours because I cannot do any of that paperwork myself, would be much more affective at resolving any of these. Doesn't appear to be enough people that you understand and have time to read the report properly anyway. It's not being reflected in the plan because their reviews and appeals come back having actually read the plan stating that the requested service anatomy is reasonable.
16. Learn what participation means! It's a two-way street. You are not listening or including us in our own scheme.
17. It is already a humiliating and difficult process, the only purpose for the government doing this is to cause further difficulties and humiliation.
18. We have gone through the lays of red tape when we applied. Getting the funding for their needs was a nightmare and as a carer it nearly broke me. Mistakes in their plan. Plan and cut back in funding because we asked for a review. I had to go to my local member continually. In the end I sat in the NDIS offices until they fixed it after months of going backwards with the departments — more complicated because of having three.
19. I should not have to prove my disability each review! Just because the system doesn't have a neat box to put me into. My condition is unusual and I have to explain my condition again and again!
20. I am so grateful for the support, and fought hard to get what I needed. I don't know what I will do if I lose it.
21. I hate the NDIS determines whether I go to university or not (it depends on my funding, and yes, I was denied funding for a support worker, which I require full time when I'm away from home, to take me to uni my first year of NDIS, so I had to postpone for 12 months!!!). I hate the feeling that my life doesn't belong to me — it belongs to some stranger I've never met. And I go through this every. single. year. My next plan review is the end of November, and hopefully I'll be going to uni next year, but who knows? We need to make the system a little more sturdy than “my planner is having a bad day and taking it out on me” system we have now.
22. They need to get their shit together. Reviews should be done by the same person each time.
23. The collaboration with the NDIA personnel is excellent and helpful. It is the LAC that is causing most concern with the way they write the report.
24. Make the process simpler and supportive.
25. I'm also an LAC.
26. I seek to be a participant and provider and as person with lived experience seem better

suited than the professionals who seem to be reintroducing still general movements assessments and barriers to those in need of support like me, as both a participant and a provider, so not only can I be empowered and accountable to reach my own full potential but to also ensure to the extent possible this is the case for others as was originally intended.

27. I had an appalling LAC at my planning meeting. She asked many questions which I felt were intrusive and she made me feel extremely uncomfortable.
28. The NDIS is the worst experience of my life and I would not wish it upon anyone. It does not understand complexity and doesn't want to. Many take so many aspects of the NDIS for granted, but fact is there is no legislated right to attend a planning meeting (I have been denied access to many of mine — and there is NO plan nominee or guardian in place?!) and nor is there a legislated obligation for them to make the planning process accessible for people. I think many people would be surprised by the level of planning meetings being conducted with no one other than an NDIS-funded support coordinator chosen by the NDIA, because there are no informal supports in place. There are many participants who the NDIA have never met, and for whom there are no informal supports, and no oversight through guardianship (while a restriction has someone else watching what service providers are doing to the person — what happens when it isn't there?).
29. Unable to get NDIS supports despite qualified evidence presented.
30. So far they have been good.
31. I am so scared of becoming an NDIS participant due to the levels of control that would be exerted in my life.
32. I am not eligible despite severe incapacitating disability. Why isn't "not eligible" an option in Question 10.
33. My daughter who lives with me has been accepted into the scheme, but has been unable to receive any significant budget or assistance. One of the most difficult areas is working with the LAC. They have been extremely difficult to work with. I don't think they are up to the job, and there have been numerous complaints, region-wide.
34. I've had a rude planner one time.
35. Some services that were beneficial have been removed — i.e. deep tissue remedial massage was available under the WA scheme but removed upon review under the Federal scheme, and has not been reinstated despite repeated requests and evidence of the benefits — less pain, easier movement, less medication required.
36. NDIS has failed.
37. NDIS wonderful Scheme. Can't survive without it. NDIS changed my life, great help. We feel included.
38. I have done an independent assessment to help someone else complete her access request and plan, and was pleased to see the Agency taking on the information and advice in her plan. It can work.
39. Too many.
40. It's been overwhelming and heartbreaking most of the time.
41. It is working for me as far as it can in regional NSW where there's not as much choice in providers and services.

42. It has been a mess to deal with. When you make a call to them it depends on how that person interprets the information to the answers you get. They don't work in the real world. They allow major-modifications contractors to get away with anything and then tell you to follow up with other agencies cause all they are doing is paying for it. If the work is substandard it falls on you to repair it, with it being NDIA controlled. But they are now asking us to keep proving our disability. Interesting.
43. I have a disability and need support but don't qualify. I feel like I'm not important/not getting the support I need to live a healthy life.
44. Three rejections and my social worker is disgusted with the assessment process. We are planning to appeal.
45. I have had bad experiences with them so far on two denied applications!
46. It's so hard to get structured, clear information. It's not geared to newly diagnosed people. People with non-physical or intellectual disabilities are not catered for.
47. I wish they would hire people who have an understanding of disability. Also I am sick of people who are using the scheme to get rich and do not understand disability.
48. NDIS is an insurance agency not a welfare agency, it behaves as such. It also favours those who have money, those with privilege (e.g. only funding mods for almost new cars, which many with a disability cannot afford, therefore cannot get them put into their community.)
49. I would like to apply for NDIS, but the support I require to participate in my NDIS application would only be available to me if I already happened to be on NDIS.
50. Plans should be flexible, to accommodate unforeseen changes in a person's life e.g. when surgery is required, or rapid deterioration in a person's disability requires increased services and therefore funding.
51. It should not require a complete Plan restart!
52. And if a person has been supported by OTs in Assistive Technology requirements, then no Planner should ever, be able to deny support, for what is being requested. We know best and have paid for the OTs to make assessments! It is not the right of the NDIA to refuse the request, based on a report, and a phone conversation and never in situ, in a person's life — that is why we have OTs to support us!!
53. So far NDIS is grossly discriminating to some people that have had a disability thrust upon them from injury!
54. Gave me a cleaning service and an art program (both very good!).
55. That outsourcing planning is a dismal failure and is further evidence of how independent assessment would be a disaster for people who really need assistance. That the frequent changes in rules and language are disturbing. That the bureaucrats need constant reminder of the intention of the scheme and that there are far too many examples of value judgements by individuals determining what can ultimately be life-threatening outcomes for participants. That not many LACs or planners actually READ the reports prepared in good faith and at significant cost.
56. The people working at the NDIS call centre fail to have any empathy and fail to help you.
57. One, main contacts are being changed before reviews so you don't get the person who helped you last time despite the policy within the participant improvement plans.

58. Drafts are not being sent out as a Supervisor said they don't have to adhere to the participant improvement plan.
59. Staff have been caught out lying even with evidence but the Team Leader says I believe my staff, so despite APS breaches nothing is done.
60. No one can explain can Reasonable & Necessary according to the decision they make, they just state I made it under Section 34 R&N. That's fine but tell me how you came to that decision. No one can actually tell you, they all hide under R&N and give you an everyday living expense example even though that is not what you were asking for.
61. Telling me how I should feel.
62. Telling my mother even though I am an adult and she does everything for me that she would be doing more.
63. Telling me that even if I require, and evidence is there, I need multiple specialists, that I only need one but refuses to tell me why or qualifies that statement.
64. Roundtable discussions of participants by staff to determine if someone is complex despite the evidence that I am.
65. Not recognising reasonable adjustment legislation exceptions and referred me to COAG agreement even though the agreement stated that the NDIS would supply information.
66. Telling me that they don't have to give me an explanation but the Act states they do.
67. More importantly I am really annoyed that so many people contributed to the workshops, their time and effort into the Service Guarantee, Service Charter and the Participant Improvement Plans and none of the staff including team leaders and supervisors believe they need to adhere to it. I believe PWDA with the support of the Senate need to get the NDIS under the Defective Administration Scheme and we will see a reduction in negative behaviours as they will be more accountable.
68. They have been average at best, and dismissive and difficult at worst.
69. The assessments are not done by educated peers and with a disability.
70. For me the NDIS has changed my life — I haven't had any problems with the system and the help and assistance has been wonderful. My long-term goal is because of my disabilities to not having to go into a nursing home as I age.
71. NDIS has changed my life but I'm extremely worried that this will change with independent assessments because my disability can be easily misunderstood.
72. It's tiring, frustrating and is designed to wear you down until you get on board, then it is tough — LACS are useful as an ashtray on motorcycle.
73. The scheme is far too complex for participants to navigate easily, Independent Assessments are just another complication that NDIA are adding to the mix.
74. Being my first year with NDIS, I have struggled with the COVID interference in trying to set up my assistance. A helping hand would have been nice and reassurance that because I was unable to access a lot of the help I require, that I won't lose my funding for next year. I just received the help that I require, was unable to access it, hopeful that it won't be taken from me before I actually get to use it.
75. All I can say is that the NDIS is a bureaucratic nightmare and no one working for the scheme/agency seems to know the answer to any questions I have. Everything takes forever but I'm stuck with it, or else I starve and have no supports. I hate how disconnected from my community it makes me feel.

76. I have tried four times to apply for NDIS and failed four times, with no assistance, at significant cost, and with no advocacy to assist.
77. There are enough inexperienced and under-qualified people already involved in NDIS.
78. The NDIA's administration can be extremely mean and hard-nosed when the participant and the participant's requested support doesn't fit neatly into their little boxes. Independent assessments could turn into a vehicle for control.
79. I am on my THIRD attempt to gain access, after 20 years on a DSP. I have found the process to be humiliating and demeaning of my struggle to manage my health problems. I don't believe I should have to beg for the assistance that I have previously received through programs that were dismantled when NDIS came online. I have been asked to provide evidence that mobility aids were necessary, asking if I "managed my weight" would my mobility issues resolve (I have psoriatic arthritis, degenerative spinal disc disease with peripheral neuropathy and advanced osteoarthritis) and told that reports from doctors and allied health professionals were insufficient to demonstrate my need for assistance. I now believe that the NDIS are deliberately being obstructive, in order to discourage people from persisting with their applications.
80. From keeping up to date and learning about NDIS prior to the rollout here, I have read through the Act and attended as many workshops regarding NDIS as I could and educated myself with knowledge to assist my life through the wonderful scheme that NDIS should provide.
81. I have found many NDIS personnel are 'just' public servants and treat me with a condescending manner or trying to bluff their way through questions that they are ignorantly uneducated to answer.
82. NDIS is a machine to provide jobs to a variety of so-called professionals, of dubious quality, to make decisions about vulnerable people's lives. Anti-constitutional.
83. The planner's background and experience significantly affects your next plan and assessments by strangers to the participant will only amplify this.
84. Very slow, poor decisions, total lack of consistency.
85. It has been more supportive than other systems although if you treat funding with respect, and as taxpayers money, and don't use it all — for reasons including inability to find supports, illness, family circumstances — then the planner often takes funds off the participant. This acts as a disincentive to treat the funding with the respect that it deserves, by using it for its highest and best uses. This is particularly worrying with the impact that COVID-19 has had on ability to access and use supports. For some of us, the vulnerable status of our family members is further reason why we cannot use our usual supports and means our health deteriorates.
86. The NDIS, while imperfect, works better than Comcare or Veterans' Affairs. It would be a shame to lower it to those standards, with the consequent destruction of human lives that have been well publicised. The NDIS should include coverage of specialists such as psychiatrists.
87. It's bloody well confusing for most people I know.
88. As an older person, I need weekly therapy to maintain my status quo physically. My therapy funding can't just be a short program with high-outcome expectations of vast improvement. To be assessed by a stranger and only given 10, 12, or 20 weeks of funding for therapies would mean a deterioration and greater overall support needs.

- 89. It has generally been positive and made it easier for me to access support. I did not have a package prior to the NDIS and had mostly negative experiences with the pre-NDIS system.
- 90. Early days were best. Privacy has deteriorated with introduction of NGO services.
- 91. Too complicated.
- 92. It's horrific. I'm terrified and exhausted for months leading up to a review, and through the review, and then while waiting for the new plan.
- 93. Still in the stages of fine-tuning and getting it right. Real cost of disability can't be quantified. Forced constant assessment just a barrier to hope of normal living.

Appendix — PWDA blog post on independent assessments

■ We Are Concerned About “Independent Assessments” For The NDIS

Last week, the Australian Government responded to the Tune Review Report, supporting, or supporting in principle, 29 recommendations to make the NDIS less complex, and to support fair access and easier navigation of the scheme.

However, like many in the disability community, PWDA is highly concerned about the additional announcement of “independent assessments”, to be conducted by healthcare professionals using standardised tools.

This goes well beyond the scope of the small pilot we supported, trialling the use of “functional assessments”, intended to move away from a reliance on medical assessments and give people with disability better access to the NDIS by covering the costs of gathering evidence, and getting reports.

People with disability are the experts in our own support needs. Building relationships with medical and allied health professionals, developing a productive, shared understanding of our individual needs, can take time, and requires a mutual commitment to building trust.

The prospect of attending compulsory assessments, with healthcare professionals we don’t know, who are unfamiliar with the particulars of our situations, with only 1–4 hours to communicate our needs and with our basic supports on the line, is highly distressing to many of us.

If we don’t agree with the independent assessor’s opinion, we are worried that we will have to go through the appeals process, which is timely, costly and may delay access to urgently needed supports.

These concerns are not unfounded. People with disability who have undergone independent assessments in other schemes, such as workers compensation schemes, have found the process stressful and hostile. Ombudsman reports have shown that some workers compensation insurers purposefully choose independent assessors who they know are more likely to recommend terminating or minimising supports. We are concerned that the same issues will arise if the NDIS starts using independent assessments.

The NDIS is meant to champion the choice and control of people with disability. As it stands, we struggle to see how a compulsory program of “independent assessments” is compatible with the stated objects of the NDIS Act.

However, as long as this remains the intended approach of the government, we would like some clarity regarding the following:

- How will a standardised assessment tool accurately capture the wildly diverse needs of people with all kinds of disability?
- How will it be ensured that an assessor has the appropriate knowledge and background to provide an assessment for any particular person with disability?
- How will the accuracy and reliability of assessors be monitored, and what will happen if there is inconsistency in how assessments are done?
- Why is there no scope to consider evidence and/or advice provided by a treating professional that a person with disability already engages with?

- What is the potential for independent assessments to have punitive effects on marginalised communities (regional and remote Australians, Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds ...)?
- Why are people who have previously been assessed as having stable functional capacity required to undertake a new assessment?
- Will all necessary supports be provided to enable participation in assessments, such as transport and communication supports?

These concerns are not exhaustive, and we need clear answers. The proposal to introduce “independent assessments” should not go ahead until we know exactly how the model will impact people participating in the scheme. The aim to introduce “individual assessments” in 2021 feels rushed given the current evidence.

We need significant and widespread consultation with people with disability on this program. Additionally, disability representative organisations like PWDA need to be resourced to consult widely with our communities.

We encourage our members to write or contact the Minister for the NDIS, Stuart Robert MP, if you would like to express your own concerns.

Stuart Robert MP
PO Box 733,
Biggera Waters,
QLD, 4216

(07) 5500 5919



PEOPLE WITH DISABILITY
AUSTRALIA

People with Disability Australia

*Raw Data, Real Insights:
Voices and views of people
with disability on the Australian
Government's plans for rapid rollout
of NDIS independent assessments*

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Published January 2021

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of our
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