# NDIS Amendment Bill Consultation: July 2024

Member Engagement Summary Report

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*NDIS Amendment Bill Consultation: July 2024 – Member Engagement Summary Report*

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## About PWDA

People with Disability Australia (PWDA) is a national disability rights and advocacy organisation made up of, and led by, people with disability.

We have a vision of a socially just, accessible and inclusive community in which the contribution, potential and diversity of people with disability are not only recognised and respected but also celebrated.

PWDA was established in 1981, during the International Year of Disabled Persons.

We are a peak, non-profit, non-government organisation that represents the interests of people with all kinds of disability.

We also represent people with disability at the United Nations, particularly in relation to the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Our work is grounded in a human rights framework that recognises the CRPD and related mechanisms as fundamental tools for advancing the rights of people with disability.

PWDA is a member of Disabled People’s Organisations Australia (DPO Australia), along with the First People’s Disability Network, National Ethnic Disability Alliance and Women with Disabilities Australia.

DPOs collectively form a disability rights movement that places people with disability at the centre of decision-making in all aspects of our lives.

‘Nothing About Us, Without Us’ is the motto of Disabled Peoples’ International.

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## Executive Summary

This summary report focuses on the feedback and concerns of People with Disability Australia (PWDA) members regarding the proposed changes contained in the National Disability Insurance Scheme (Getting the NDIS Back on Track No.1) Bill 2024, and is being provided as a supplementary submission to the [Senate Community Affairs Legislation Committee's](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/NDISAmendment24) second Inquiry into the Bill.

PWDA remain steadfast in its resolve to represent the views of our diverse national membership. Amidst community concern about changes to the NDIS, we held a series of consultations with our members across the country including members’ forums and a survey.

This summary report contains the feedback we have heard from people with disability, a significant portion of whom are NDIS participants as of Friday 26 July 2024. The survey was released on 11 July 2024 and closed on 28 July 2024. As of 26 July 2024, a total of 724 people had responded to the survey with 351 of those being a NDIS participant (48%). Two member forums were held on 18 July, with a total of 29 people attending those forums.

It was clear from our consultations that people with disability are overwhelmed by the proposed changes to the NDIS, following a history of stress, fear and trauma associated with navigating and fighting for NDIS support. The potential for the loss of support carried an emotional and psychological burden, with more than two thirds of people overall (69%) believing the changes will not cover all support needs.

A staggering 90% of people believe the proposed changes to the NDIS do not align with the original vision of the NDIS. Members emphasised the need for the NDIS to be more accessible and inclusive, ensuring that all individuals with disability can easily navigate and benefit from the life-changing scheme.

People with disability want more transparent and inclusive policy-making processes. Members advocated for greater involvement of people with disability in decision-making and in the governance of the NDIS, as 90% of people think the changes overall will make it harder for people with disability to access justice and defend their rights if they don’t get the support that they need.

Consistent with the above, people shared concerns about the adequacy of funding and resources allocated to the NDIS. Members highlighted the importance of sufficient funding to meet the diverse needs of people with disability. More than two thirds (67%) of respondents believe that the changes will not adequately support marginalised groups.

Feedback from members also pointed to the need for improvements in the quality and delivery of services under the NDIS. Members stressed the importance of having well-trained staff and efficient service delivery mechanisms. However, 87% or almost nine in every ten respondents are not very or not at all confident that they would get enough information and help to use the review and appeal process.

Our consultation with our members provided many key insights into what people with disability are thinking about proposed changes to the NDIS. These insights must be considered fulsomely by the Committee, and we trust the views of our national membership will support recommendations that address the concerns people with disability have with the Bill and related changes to the NDIS.

### Methodology

Due to rounding not all tables or graphs will add to 100%. For questions where respondents were allowed to select more than one response the total will exceed 100%.

All responses – not just those that were completed – were included. Please see the note at the bottom of each table for the base per question and/or cohort.

For the full methodology for this project please contact People with Disability Australia.

Data presented in this report is inclusive of responses provided up to 26 July 2024.

# Key insights

### General view of the changes

* Nine in ten (90%) of respondents do not believe that these changes align with the original vision of the NDIS to empower people with disability. Participants in the member forums argue that the proposed changes place both the risk and burden in accessing the system on people with disability themselves.
* More than two in every three respondents overall (69%) believe that the new system will not cover all their necessary supports.
* More than nine in ten (93%) respondents overall believe that removing access to the NDIS will go against the UNCRPD right for people with disability to have the right supports that let them live independently and be included in the community.
* The vast majority are worried that the changes could
  + result in groups of people with disability being treated unfairly (93%)
  + exclude people from the NDIS who need support (89%)
  + make it harder for people with disability to access justice and defend their rights (90%)
  + move the NDIS towards a more NDIA controlled, top-down model (84%)
* More than two thirds (67%) of respondents believe that the changes will not adequately support marginalised groups.

### Choice and control

* Maintaining and enhancing choice and control is of critical importance to respondents and was repeatedly one of the most common themes in both the member forums and the open-ended responses in the survey.
* In this context, most respondents believe that the proposed changes will not give them more choice and control over their supports (81%). Furthermore, under a personalised budget system specifically, most (60%) believe they would have very little or no choice over their supports.
* More than four in five (84%) respondents are concerned about the stricter rule on how flexible funding can be spent.
* More than three-quarters (78%) of respondents feel that the introduction of “stated supports” adds unnecessary complexity to the funding model.

### Interacting with the NDIS

* Over half (54%) of respondents have asked for a review because there funding request was declined.
* Over half (57%) of respondents have had trouble responding to NDIS requests because of a crisis or complex needs.
* Proposed assessment process
* More than nine in ten (92%) are not confident the proposed assessment process would properly understand all their support needs.
* Both survey respondents and participants in the member forums argue that disability is complex, and their needs fluctuate. Both also commented on the poor training and understanding of assessors.
* Most (87%) dislike the idea of the NDIA choosing their assessor – more than three-quarters ‘dislike it a lot’ (77%).
* Most believe that:
  + assessment tools should be co-designed with people with disability (93%)
  + there should be more transparency and legal rights around assessment reports (92%)
  + the proposed changes for assessing who gets access to the NDIS are unfair (81%)
* Participants in the forums also argue that assessments should be undertaken by someone known to the participant, who understand the complex nature of their disability.

### Reviews & assessments

* Three quarters (75%) of respondents worry about losing access to funding if they cannot respond to a request in 90 days. Members in the forums commented that it would be almost impossible to be seen by a Specialist in that time, should that be required.
* Survey respondents argued that the NDIS can’t meet a 90-day turn-around, and it is unfair to ask this of participants.
* Almost three-quarters of respondents (71%) overall believe it is unreasonable for the NDIA to request any information they want from them.
* More than four in every five respondents (86%) would be uncomfortable having to see a NDIA-appointed assessor to stay in the NDIS. Members in the forums suggested that this could be traumatic for some participants, especially those who have experienced medical trauma in the past.
* More than four in every five (86%) respondents overall say that the NDIA’s proposed information gathering powers conflict with the UNCRPD rights regarding a right to privacy and to make free choices.

### Challenging Decisions

* Almost all respondents (98%) believe it is either extremely or very important for them to have clear rights to challenge NDIA decisions they disagree with.
* Almost all (95%) respondents believe there should be guaranteed funding for advocacy to help people with disability engage with NDIS processes.
* Almost all respondents (95%) are worried that the proposed changes will make it harder for them to get an independent review of decisions about their NDIS supports.
* Four in five respondents (80%) do not believe that the review and appeal rights in the new NDIS law are clear and strong enough.
* 87% - or almost nine in every ten respondents – are not very or not at all confident that they would get enough information and help to use the review and appeal process.

### Rules and categories for supports

* Almost two-thirds (64%) of respondents say they dislike the idea of there being set rules and categories for NDIS supports.
* 85% of respondents are worried that important supports they need won’t fit within the new rules.
* Respondents had numerous examples of using their supports flexibly, including purchasing from mainstream suppliers to save money and investing in appliances that would in turn cut down on the need for support workers.
* Almost three-quarters (73%) of respondents say that the new support rules will make it harder for them to live independently.
* More than half (59%) of respondents said it would be difficult for them to show they still need NDIS support under the new rules.

### Debts incurred from unapproved items

* Most (60%) believe it is unreasonable to make participants pay back money spent on unapproved items.
* Respondents to the survey thought this was unreasonable due to a lack of clarity around the rules and a belief that errors are often not the participants faults (i.e. they are advised by support coordinators). They believe these changes will cause extreme distress – with parallels drawn with robo-debt.

### Impairment Classes

* Almost all (94%) of respondents believe that all of a person’s disabilities, impairment type and whole of life circumstances should be considered together when considering access to the NDIS.
* Most (88%) respondents believe that not considering their disabilities, impairment type and whole of life circumstances together would make accessing the supports they need harder.
* Respondents in the survey commented that this change in particular would lead to a loss of holistic care, impacting on their quality of life.
* Most (89%) respondents said that defining and treating people differently based on their impairment type without considering all their disabilities and whole of life circumstances does not align with the UNCRPD rights regarding the right to equal treatment and non-discrimination.

### Foundational supports and mainstream services

* Most respondents:
  + believe that the rollout of “foundational supports” in July 2025 is not realistic or well-supported (81%)
  + are not confident that mainstream systems can meet their disability support needs (87%)
  + believe it is unlikely they would get the same level of support from a mainstream service instead of the NDIS (89%)
  + are worried that shifting supports out of the NDIS and back to the states/territories will make it harder to get help (89%)
* For respondents in the survey, the implementation of foundational supports will lead to a reduction in support quality and access, and will increase the complexity and administrative burden in trying to access supports. Respondents also believe that States/Territories have inadequate funding to roll this out.

### Co-design and trust in government

* Almost all (97%) respondents believe that it is extremely or very important that people with disability help shape the NDIS rules and processes.
* The need for co-design was repeated throughout both the survey comments and the member forums.
* 90% of respondents overall do not trust the government to design the new NDIS in a way that works for them, without input from people with disability.
* 93% of respondents overall believe there is too much danger in passing legislation without the rules and assessment tools being written in a co-design process with people with disability.

# Summary of findings – Member survey

### 1.1 Disability type

**Question:** If you are a person with a disability or a parent, carer or nominee, what is your main disability type (or the disability of the person you support)? (select all that apply)

|  |  |  |
| --- | --- | --- |
|  | **TOTAL** | **PWDA Member** |
| Physical disability | 54% | 61% |
| Intellectual disability | 23% | 19% |
| Psychosocial disability | 30% | 28% |
| Autism | 40% | 32% |
| Neurological disability | 30% | 30% |
| Sensory disability (vision, hearing etc.) | 16% | 15% |
|  | *n=724* | *n=351* |

**Comments:**

Of those that responded to this question (those with a disability or their carer/s):

* More than half (54%) live with a physical disability.
* Four in ten (40%) live with autism.
* Almost one third live with a psychosocial disability (30%) or a neurological disability (30%).
* Almost one quarter (23%) live with an intellectual disability, while less than one in five live with a sensory disability (16%).

### 1.2 Registration of all NDIS providers

**Question**: Which of the following apply to you?

|  |  |  |
| --- | --- | --- |
|  | **TOTAL** | **PWDA Member** |
| I am a person with a disability | 68% | 79% |
| I am a NDIS participant | 50% | 64% |
| I am a nominee | 19% | 17% |
| I am an informal carer, parent or guardian (here on ‘carers’) | 36% | 33% |
| I am a disability service provider or worker | 14% | 9% |
| I am an allied health professional | 8% | 6% |
|  | *n=724* | *n=351* |

**Comments:**

The most common respondents to this survey were:

* People with disability (68%)
* NDIS participants (50%)
* Informal carer, parents or guardians (36%)

A further almost one in five are a nominee, and 14% are a disability service provider or worker. Less than one in ten (85%) are an allied health professional.

**Question. Is there anything else you would like to tell us about you?**

Most commonly the respondents mentioned that they live with both **Autism and ADHD**. Commonly these respondents were newly diagnosed and had a late diagnosis.

Respondents also commonly mentioned that they **waiting to join the NDIS** or have **previously been denied access to the NDIS**.

Others commented that they **are both a person with disability and a carer/family member of a person with disability.**

A final group gave the **specifics of their disability or disabilities**.

### 1.3 Level of understanding of the changes

**Question:** How well do you understand these proposed changes?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Understand** | **57%** | **54%** | **54%** | **51%** |
| I understand very well | **19%** | 16% | 19% | 15% |
| I understand pretty well | **38%** | 38% | 35% | 36% |
| I understand a little bit | **34%** | 36% | 36% | 38% |
| I don’t understand at all | **9%** | 11% | 10% | 11% |
|  | *n=540* | *n=372* | *n=260* | *n=274* |

**Comments:**

* Just over half (57%) of respondents say that they understand these proposed changes well or pretty well.
* NDIS participants themselves (51%), PWDA members (54%) and people with disability (54%) are less likely to say that they understand these changes very or pretty well.
* Service providers or support workers (77%), carers (62%) and allied health professionals (76%) were more likely to state that they understand these changes.

### 1.4 Information sources

**Question:** Where have you got information about the changes?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Disability organisations | 32% | 33% | 38% | 34% |
| Social media | 25% | 26% | 23% | 25% |
| Government websites | 19% | 16% | 16% | 15% |
| TV, radio or newspapers | 10% | 9% | 9% | 9% |
| Friends, family or support workers | 5% | 6% | 5% | 6% |
| I haven't got any information | 9% | 10% | 8% | 11% |
|  | *n=530* | *n=364* | *n=253* | *n=265* |

**Comments:**

* Overall, the three most common sources of information about the changes are:

1. Disability organisations (32%)
2. Social media (25%)
3. Government websites (19%)

* This was followed by TV, radio or newspapers (10%) and friend, family or support workers (5%).
* Almost one in ten respondents overall haven’t got any information.

The most common sources of information are consistent across the key cohorts of people with disability, PWDA members and NDIS participants.

More than one in ten NDIS participants haven’t got any information about the changes to the scheme.

### 1.5 Feedback for the government

**Question:** If you could tell the government the most important thing to get right in the NDIS changes, what would it be?

**The key themes raised (from most to least common) were:**

1. Maintain a focus on “**choice and control**.”
2. Ensure any changes include **consultation and co-design** – and that a diverse range of people with disability are represented in the co-design process.
3. Ensure the NDIS is **flexible** and able to respond to **individual needs**.
4. **Consult**, **respect** and **listen** to people with disability in general (not just in the co-design process).
5. Improve the **transparency** and **accountability** processes within the NDIS in general.
6. Ensure **support is provided to people with disability in need** – specifically, that people with severe disabilities are adequately supported and those with autism maintain funding.
7. Improve **training** and **quality of service** by NDIS staff and support workers.
8. **Reduce** **bureaucracy** and **simplify** processes.
9. Respect the **human** and **legal** **rights** of people with disability.
10. Address fraud and the misuse of funds – particularly providers overcharging.

**Quotes**

“The NDIS participant and their carers have personal choice and say in what the money gets spend on."

“Include a large and diverse range of people with disabilities in co-design and approval of changes."

"Treat people as the individuals they are, with their unique lived experience."

"We need more transparency in decision-making processes so that participants can understand how decisions are made and ensure they are fair."

“Make sure that everyone, regardless of the severity of their disability, receives the supports they need to lead fulfilling lives."

“Stop cutting supports to participants. Stop making life more difficult than necessary."

"Training their staff &/or employing more people with disability so plans that enable choice, control & access to adequate supports are provided."

“Ensuring disabled people’s rights are protected and maintained."

“Crack down on businesses overcharging and those rorting the system without making the rest of us suffer."

### 1.6 Suggested improvements to the NDIS changes

**Question:** How could the NDIS changes be improved to better respect the rights of people with disability?

The responses to this question reflected the key themes from the previous (‘feedback for the government’). The key themes raised (from most to least common) were:

1. Maintain or enhance participant “**choice and control**”.
2. Ensure changes are implemented after **co-design and consultation**.
3. Improve **transparency** and **communication** around the NDIS in general and the proposed changes.
4. **Align** the NDIS practices with **international human rights standards**.
5. **Enhance mechanisms** for **accountability** and **oversight** to **prevent fraud** and misuse.
6. Improve the **quality**, **qualifications** and **training** of **assessors** and **plan** managers.
7. Allow more **flexibility** in how funds are used and which supports are chosen (to meet **individual needs**).
8. Reduce **bureaucracy** and **simplify** both **access** to the scheme and **management** of supports.

**Quotes**

“Recognise that having a disability doesn't mean you can't make decisions for yourself or manage your own affairs."

"Extensive consultation with PWD, their families, and other key stakeholders."

"The legislation is horribly unclear. What is the mechanism for determining budgets?"

"Should be in line with UNCRPD don’t take away right of appeal."

"Make providers and NDIA accountable for errors and fraud."

"Staff should not be able to insert their personal opinions on specific disabilities into their decision making."

"Allow for participants to provide statements to put supports recommended by professionals into context."

"Make it less complicated so it is easier for participants to understand."

**Question:** Is there anything else you would like to tell us about this?

Following their initial comments which focused more heavily on specific suggestions for the NDIS, these additional comments demonstrated dissatisfaction with how the NDIS operates, and delved into deeper, systemic issues. These comments also focused more on the impacts of these problems on current and prospective participants in the scheme.

The key themes raised (from most to least common) were:

1. Concerns about **costs** and general **issues** with **providers**.
2. **Bureaucratic** challenges and **system inefficiency** (including gatekeeping).
3. Concerns over **personal autonomy** and **choice**.
4. **General concerns** about the **proposed** **amendments**
5. **Concerns** about **current** or **future** **mental health** and **emotional** **impact**s of the **proposed changes**.
6. **Assessments** need to be **undertaken by people who will truly understand** the needs of the applicant.
7. Funding **inequality** and **mismanagement** (including overpricing by providers, mismanagement of funds and administrative inefficiency), and the impact of **funding cuts** (uncertainty and instability).

**Quotes**

“Recognise that having a disability doesn't mean you can't make decisions for yourself or manage your own affairs."

"Cut the bureaucracy, stop the gatekeeping, enable people to talk directly with a planner when they need to."

"Nobody should be making decisions about what I do and don't need. Everybody's different."

"This bill denies the participant the right to procedural fairness and should not be passed."

"I feel victimised and de-humanised by the Minister’s public and factually inaccurate attacks."

"Assessments of a participants needs which determine level of supports need to be undertaken by those that are familiar with the individual."

“As a support worker, I get very tired of some people on NDIS getting more opportunities than others. For example, some get approved for respite while others are rejected."

“Cutting funding to disabled people will mean a decrease in quality of life, independence, social connectedness, participation in the labor workforce etc. If you want us to work towards being contributing members of society do not take away supports we rely on."

### 1.7 Belief in the changes delivering more choice and control

**Question:** Do you think these changes will give you more choice and control over your supports?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | 5% | 4% | 5% | 2% |
| No | 81% | 81% | 82% | 85% |
| Not Sure | 14% | 15% | 13% | 11% |
|  | *n=521* | *n=359* | *n=252* | *N=263* |

**Comments:**

* Overall, more than four in five respondents (81%) do not believe that the changes will give them more choice and control over their supports.
* This view is consistent amongst those with disability (81%), PWDA members (82%) and NDIS participants (85%).

### 1.8 Experience requesting a review

**Question:** Have you ever asked for a review because your funding request was declined?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | 54% | 51% | 57% | 55% |
| No | 39% | 40% | 7% | 4% |
| Not Sure | 7% | 4% | 41% | 40% |
|  | *n=515* | *n=354* | *n=251* | *n=262* |

**Comments:**

* Over half (54%) of respondents have previously asked for a review because there funding request was declined.
* 39% of respondents say they have not asked a review and 7% are not sure.
* PWDA members were slightly more likely to request a review (57%), as were NDIS participants (55%).

### 1.9 Difficulty responding to NDIS requests

**Question:** Have you ever had trouble responding to NDIS requests because of a crisis or complex needs?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **57%** | 61% | 58% | 61% |
| No | **35%** | 32% | 32% | 33% |
| Not Sure | **8%** | 7% | 6% | 6% |
|  | *n=520* | *n=360* | *n=253* | *n=266* |

**Comments:**

* Over half (57%) of respondents have had trouble responding to NDIS requests because of a crisis or complex needs.
* This rises to 61% of both people with disability and NDIS participants, and 58% of PWDA members.

### 1.10 Review of NDIA decisions

**Question:** How confident are you that this assessment process would properly understand all your support needs?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL Confident** | **6%** | **4%** | **6%** | **3%** |
| **TOTAL Not Confident** | **92%** | **95%** | **92%** | **96%** |
| Very confident | **2%** | 2% | 2% | 1% |
| Somewhat confident | **4%** | 2% | 4% | 2% |
| Not very confident | **12%** | 12% | 12% | 11% |
| Not at all confident | **80%** | 83% | 80% | 85% |
| Not sure | **2%** | 1% | 2% | 1% |
|  | *n=503* | *n=348* | *n=247* | *n=257* |

**Comments:**

* More than nine in ten respondents (92%) are not confident that this assessment process would properly understand all their support needs.
* This rises to 96% of NDIS participants and 95% of those with disability.

### 1.11 Concern about funding due to an inability to respond

**Question:** Do you worry about losing access to funding if you cannot respond to a request in 90 days for revocation of your participant status or 28 days for a planning process?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **75%** | 79% | 78% | 82% |
| No | **14%** | 11% | 12% | 11% |
| Not Sure | **11%** | 10% | 11% | 7% |
|  | *n=504* | *n=348* | *n=247* | *n=257* |

**Comments:**

* Three quarters (75%) of respondents worry about losing access to funding if they cannot respond to a request in 90 days.
* More than four in five NDIS participants (82%) worry about this, as do more than three-quarters of PWDA members (78%) and people with disability (79%).

**Question.** Is there anything else you would like to tell us about this?

The key themes raised by participants are outlined below.

* **Bureaucratic delays and inefficiencies**

Respondents expressed frustration over the NDIS's slow and inefficient processes, particularly with the extended times for plan reviews and decisions.

"How about the ndis sticking to the 90 day turnaround. 6-12mths waiting for a review is simply not good enough."

"We complied with all the reporting and timing to allow for a continuation of the plan and NDIA didn’t process the information supplied which then resulted in plan not being continued and we had to go through the process of getting a new plan."

* **Lack of consistency and transparency**

Respondents are concerned about inconsistent decision-making within the NDIS and a lack of transparency.

"Decisions need to be reviewable with clear transparency and accountability.”

"Some of the decisions that the NDIS have made about request that we have made have made no sense to me as I feel it would have saved them money in the long run. I have seen a lot of this; it is ridiculous in my eyes why would you not want to save money."

* **Challenges with accessibility and communication**

The system is seen as difficult to navigate, especially for those with complex needs who struggle with rigid communication protocols and service accessibility.

"The system is punitive and inaccessible. I am Disabled and also a carer and nominee. I am too sick and time poor to jump through all the hoops they require."

"There is no clear way to contact the NDIS when needed."

* **Concerns about funding reductions and restrictive policies**

Respondents are highly concerned about funding cuts and the potential lack of flexibility about what services and supports can be funded.

"My son's funding was cut due to a lack of documentation, when we reconnected him with the correct documentation they cut his funding by 20%."

"Carer’s Qld did my annual review. They said my plan would roll over. Then NDIA changed it and cut my funding."

* **Issues with service providers and quality of care**

Respondents highlighted problems with finding quality care and issues with service providers, including disputes over services provided and concerns about the providers' qualifications.

"Again, so far we have had 4 different service providers who are meant to help us. To date, I have no idea who our 'helper' is.”

"Been abused by service providers as well as NDIA delegates."

* **Effects of changes on vulnerable populations**

There are strong concerns about how the changes might impact vulnerable groups, particularly those with severe disabilities and chronic conditions.

"Participants and their families live under constant fear of threat and reprisals by the NDIA."

"This proposed legislation acts to penalise and deny the most vulnerable people on the scheme the right to support, by way of threats, intimidation and punishment. Further, I believe most people who are going to be most targeted would not be aware of this situation."

* **Demand for personalised and respectful treatment**

Respondents want more personalised interactions that respect their unique needs, rather than being treated merely as numbers within a bureaucratic system.

"The NDIS needs to be an individualised program. No two people are exactly alike but it seems you will need to fall into a particular box which allocates your amount of funding."

"The very nature of being disabled makes it difficult to respond within time limits. The nature of the disability must also be taken into consideration."

* **Emotional and psychological burden**

Respondents are highly concerned about the stress, fear, and trauma associated with navigating the NDIS, especially regarding the potential loss of supports and/or the need to continuously ‘prove’ they are a person with disability.

"The fear of being cut off creates such undue stress and trauma."

"I'm scared and overwhelmed by the burden that’s been placed on disabled people over the past few years."

### 1.12 Support for rules and categories for NDIS supports

**Question:** Do you like the idea of there being set rules and categories for NDIS supports?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| **TOTAL: Like it** | **19%** | **16%** | **13%** | **14%** |
| **TOTAL: Dislike it** | **64%** | **67%** | **68%** | **70%** |
| I like it a lot | **8%** | 6% | 6% | 5% |
| I like it a little | **11%** | 10% | 7% | 9% |
| I dislike it a little | **9%** | 7% | 9% | 7% |
| I dislike it a lot | **55%** | 60% | 59% | 63% |
| I’m not sure | **17%** | 18% | 19% | 16% |
|  | *n=504* | *n=349* | *n=247* | *N=258* |

**Comments:**

* Almost two-thirds (64%) of respondents say they dislike the idea of there being set rules and categories for NDIS supports. 55% - more than half – dislike it a lot.
* NDIS participants (70%) are more likely to dislike these set rule, as are PWDA members (68%) and people with disability (67%).

### 1.13 Concern about the new rule excluding their supports

**Question:** How worried are you that important supports you need won't fit the new rules?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with disability** |
| Yes | 56% | 55% | 60% | 54% |
| No | 20% | 23% | 13% | 22% |
| Not Sure | 23% | 22% | 27% | 24% |
|  | *n=202* | *n=150* | *n=52* | *n=184* |

**Comments:**

* Just over half of both members (56%) and NDIS participants (55%) support this proposal.
* Amongst members, just one in five (20%) do not support it while 23% are ‘not sure’.
* Less than a quarter (23%) of NDIS participants do not support it, with a further 22% being ‘not sure’.

### 1.14 Examples of the flexible use of supports

**Question**: Is there anything else you would like to tell us about this?

Examples of the flexible use of supports fell into several key categories. These are listed below along with examples:

* **Health and Mobility Aids:**

"Using a phone stand designed for selfies as a holder over my bed."

“Using a children's car activity station as a lap desk so that I can do leisure activities from the couch, my recliner chair or bed."

"I have purchased compression tops and leggings from an outdoor clothing company because they are made of wool which provides temperature regulation properties."

* **Therapeutic and Psychological Support:**

"Support to manage Stiffness" remedial massage for Parkinson's Disease, recommended by all health professionals for the disability!"

“Access to psychology has helped with life planning and goal setting living with my condition.”

“Capacity Building funding to keep me well during a mental health crisis.”

* **Daily Living and Personal Care:**

"Using kitchen aprons as bibs for eating in bed, which work better than traditional options."

“Having hair washed and dried weekly at hairdresser - costs me $40 and 1.5hrs of my time. To have a support worker do the exact same thing I would need an extra 1-2hrs of support at approx cost of $60.”

* **Community Access and Social Participation:**

"Using a Guide Dog maintenance budget to fund taxis and Ubers for safe transport."

“Our support worker will often invite out my higher needs child’s friends or siblings, by the support workers choice to improve social interaction and inclusivity. I support this.”

* **Emergency and Unforeseen Needs:**

"Had to use core support for STA as SIL application declined."

"Using core funding to pay for approved supports when other categories have run out of funding."

"When my daughter ran out of funding for support workers- core budget, i asked our support workers to bill the CB category as therapy assistants."

* **Household Adjustments and Modifications:**

"Buying a robovac for more independence in maintaining cleanliness."

"Some minor kitchen mods like adding in inner drawers to the pantry that make it much easier to do things in my kitchen."

"Claiming difference in cost to upgrade appliances like new dishwasher and furniture like recliner couch to a disability friendly version of dish drawers and electric controls."

Purchasing from mainstream suppliers was often cheaper and easier than disability supports. Several also commented on investing in appliances etc. that in turn cut down on the need for support workers.

**Question:** Is there anything else you would like to tell us about this?

**Comments:**

* A very large majority (87%) of members believe NDIS plan budgets should increase in line with CPI.
* NDIS participants (88%) were only slightly more likely to believe this.

### 1.15 Concern about the new rule excluding their supports

**Question:** The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) says people with disability have the right to live independently in the community. The UNCRPD is an important international agreement that Australia has signed onto which clarifies how all human rights apply to people with disability. Do you think the new NDIS support rules will make it easier or harder for you to live independently?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| **TOTAL: Easier** | **5%** | **6%** | **4%** | **4%** |
| **TOTAL: Harder** | **73%** | **78%** | **73%** | **79%** |
| Much easier | 3% | 3% | 2% | 1% |
| A bit easier | 2% | 3% | 2% | 3% |
| No difference | 9% | 8% | 7% | 8% |
| A bit harder | 13% | 14% | 13% | 14% |
| Much harder | 60% | 62% | 60% | 65% |
| Not sure | 13% | 11% | 15% | 10% |
|  | *n=506* | *n=351* | *n=248* | *n=259* |

**Comments**:

* Almost three-quarters (73%) of respondents say that the new NDIS support rules will make it harder for them to live independently. Six in ten (60%) say it will make it much harder.
* NDIS participants (79%) and people with disability (78%) are much more likely to say that these support rules will make it harder for them to live independently. PWDA members (73%) do not differ from the overall sample.

**Question**. Is there anything else you would like to tell us about this?

* **General concerns about reduced independence**

"I'm worried about being forced onto agency management for using my supports as medically necessary, being told that's 'fraud', getting a debt raised, and losing that funding - and my community access - also."

"Participants won't have the funding to live independently or as they wish. They will be forced into environments they don't wish to be in."

"I'm 62 with a progressive neurological disease. The thought of being forced into a group home horrifies me. I would rather be dead."

* **Increased restriction**

"The new categorisation will limit choice and options, and remove availability for thousands of participants."

"The point of the NDIS is to provide choice and control. The new changes limit this significantly."

"I'm terrified of losing NDIS, or having such restricted access to supports, that I won't be able to continue living."

* **Lack of personalised care and flexibility**

"Having set categories means less flexibility to look at what is best for the participant. One size has never fitted all for any social or community support.

"My condition is rare. I have some unique needs because of this that currently seem to not be understood by NDIS planners."

"I am very concerned about forcing NDIS participants to use only NDIS registered supports."

* **Concerns over group living and shared supports**

"The new rules will force people into group homes regardless of evidence submitted."

“I know people who live independently in their own homes with 1:1 support are having longstanding funding for this stopped and are being told they need to live with other people with disabilities and share the funding."

"My son has only just moved into an SDA house. If he were forced to live with other people he would not cope and would likely reach extreme levels of anxiety."

### 1.16 Support for the NDIA choosing their assessor

**Question:** How much do you like the idea of the NDIA choosing your assessor?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| **TOTAL: Like it** | **6%** | **3%** | **4%** | **2%** |
| **TOTAL: Dislike it** | **87%** | **90%** | **88%** | **90%** |
| I like it a lot | **4%** | 1% | 3% | 1% |
| I like it a little | **2%** | 2% | 1% | 1% |
| I dislike it a little | **10%** | 10% | 10% | 10% |
| I dislike it a lot | **77%** | 80% | 78% | 80% |
| Not sure | **7%** | 6% | 7% | 8% |
|  | *n=502* | *n=347* | *n=246* | *n=258* |

**Comments:**

* More than four in five respondents (87%) dislike the idea of the NDIA choosing their assessor – more than three-quarters ‘dislike it a lot’ (77%).
* The results are similar for people with disability (90%), PWDA members (88%) and NDIS participants (90%).1.17 Co-design of assessment tools

### 1.17 Co-design of assessment tools

**Question**: Do you think the assessment tools should be co-designed with people with disability?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| Yes | **93%** | 94% | 94% | 94% |
| No | **3%** | 2% | 2% | 2% |
| Not Sure | **5%** | 4% | 4% | 4% |
|  | n=504 | n=348 | n=247 | n=257 |

**Comments:**

* More than nine in ten respondents (93%) believe that these assessment tools should be co-designed with people with disability.
* This rises to 94% of those with disability, PWDA members and NDIS participants.

### 1.18 Level of choice and control under a personalised budget system

**Question**: How much choice and control do you feel you would have over your supports under a personalised budget system?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Some/A lot/Complete choice** | **28%** | **25%** | **25%** | **24%** |
| **TOTAL: Very little/No choice** | **60%** | **64%** | **61%** | **66%** |
| Complete choice and control | 6% | 7% | 7% | 6% |
| A lot of choice and control | 7% | 6% | 6% | 6% |
| Some choice and control | 15% | 12% | 12% | 12% |
| Very little choice and control | 30% | 32% | 28% | 33% |
| No choice and control | 30% | 32% | 33% | 33% |
| Not sure | 12% | 12% | 13% | 10% |
|  | *n=504* | *n=349* | *n=247* | *n=258* |

**Comments:**

* Six in ten respondents overall (60%) believe that under a personalised budget system they would have very little or no choice over their supports.
* Just 13% believe they will have a lot or complete choice, while a total of 28% believe they will have some, a lot or complete choice.
* Two in every three NDIS participants (66%) believe they will have very little or no choice, as do64% of people with disability and 61% of PWDA members.

**Question**. Is there anything else you would like to tell us about this?

Those who said they would have **very little or no choice and control** (the vast majority) made comments that fell into the following five themes:

1. Lack of **assessor expertise** and understanding of **specific disabilities**

This includes a lack of knowledge regarding various specific disabilities – and is particularly concerning for those who have rare or complex disabilities.

1. General **concerns** about loss of **choice and control**

The proposed changes could lead to reduced autonomy in regards to selecting and managing their own supports. This would undermine a key, foundational aspect of the NDIS.

1. Fear in **reduction** in **personalised supports** and **budget constraints**

Many fear that the proposed changes are designed around cost-cutting, which will lead to reduced support and insufficient funding to meet their needs. Respondents are also concerned about a more rigid budgeting system that would force them to chose between supports.

1. Comments regarding **negative past experiences** and **distrust of the system**

This included past negative experiences with assessments and plan management.

1. **Inadequacy of assessment tool**s and processes

This includes issues such as the lack of suitable and effective assessment methods that genuinely reflect their living conditions and requirements.

**Quotes**

"A major problem currently and one which the changes will make worse is that most NDIS assessors have little or no practical knowledge of particular disabilities."

"By only allowing registered providers, participants will have less choice and control."

"The only way a personalised budget can work for government is if it is underfunded. So the only choice and control would be to choose one need over another. Hardly a choice."

"Currently the assessors have no formal training or understanding of the complexity of disabilities and instead make personal assessments based on their KPIs and prejudices."

“I had pages of reports and letters from my various specialists, gp, OT and psychologist and when applying initially for the NDIS, they based their decision on one visit and report from an OT appointed by them."

### 1.19 Adequacy of funding under the new system

**Question**: Do you think funding under the new system would cover all your necessary supports?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| Yes | **5%** | 4% | 5% | 4% |
| No | **69%** | 70% | 72% | 71% |
| Not Sure | **26%** | 26% | 22% | 25% |
|  | n=502 | n=348 | n=247 | n=256 |

**Comments:**

* More than two in every three respondents overall (69%) believe that the new system would not cover all their necessary supports.
* This rises to 71% of NDIS participants, 72% of PWDA members and 70% of those with a disability.

### 1.20 Transparency and legal rights around assessment reports

**Question**: Do you think there should be more transparency and legal rights around assessment reports?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **92%** | 92% | 93% | 91% |
| No | **2%** | 2% | 1% | 2% |
| Not Sure | **6%** | 6% | 6% | 7% |
|  | *n=503* | *n=349* | *n=247* | *n=257* |

**Comments:**

* More than nine in ten (92%) believe that there should be more transparency and legal rights around assessment reports.
* This view is consistent amongst PWDA members (93%), people with disability (92%) and NDIS participants (91%).

**Question**: Is there anything else you would like to tell us about this?

The key themes raised (from most to least common) by those who responded to this question were:

1. General comments that the **NDIS lacks transparency** and the **information** provided is **not accessible**.

Respondents commented that it is difficult to understand why certain decisions are made about their plans and funding.

1. Desire for **clear** and **accessible legal rights** and **review** processes

This is particularly important in the assessment process.

1. **Inadequacies** of the **current assessment process**

This includes both the methods of assessment and the qualifications/skills/knowledge of assessors.

1. Desire for **fair** and **personalised** **assessments**

Assessments should be more personalised, and consider the unique circumstances of each individual.

1. Concerns about **the impact of inadequate funding and resources**

Respondents repeated concerns that inadequate funding would leave them unable to access the supports they need.

**Quotes**

“All assessments reports and funding calculations should be made available on request."

“Every report should be available and given to nominee. Nothing should be hidden."

"Assessment should be appealable with the right to counter using your own reports."

"Assessments need to support the person not follow a plan, this needs to be flexible according to a person's needs as they can change quickly."

"Assessments are best done by practitioners who know the person."

"I already don’t receive enough funding to cover my necessary supports, I have had to privately fund necessary supports while on the NDIS."

### 1.21 Reasonableness of NDIA requests for information

**Question**: How reasonable do you think it is for the NDIA to request any information they want from you?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Reasonable** | **25%** | **20%** | **25%** | **22%** |
| **TOTAL: Unreasonable** | **71%** | **76%** | **72%** | **75%** |
| Very reasonable | 7% | 4% | 6% | 4% |
| Somewhat reasonable | 18% | 16% | 19% | 18% |
| Somewhat unreasonable | 20% | 17% | 17% | 17% |
| Very unreasonable | 51% | 59% | 55% | 58% |
| Not sure | 3% | 3% | 4% | 4% |
|  | *n=498* | *n=344* | *n=245* | *n=254* |

**Comments:**

* Almost three-quarters of respondents (71%) overall believe it is unreasonable for the NDIA to request any information they want from them.
* Over half (51%) believe this is very unreasonable.
* Three-quarters of both people with disability (76%) and NDIS participants (75%) also believe it is unreasonable for the NDIA to request any information they want from them. PWDA members are only slightly more likely than the overall sample to hold this view (72%).

### 1.22 Level of comfort with having to see an NDIA appointed assessor

**Question**: How comfortable would you feel having to see an NDIA-appointed assessor to stay in the NDIS?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Comfortable** | **10%** | **7%** | **10%** | **8%** |
| **TOTAL: Uncomfortable** | **86%** | **88%** | **86%** | **88%** |
| Very comfortable | 4% | 2% | 4% | 2% |
| Somewhat comfortable | 6% | 5% | 6% | 6% |
| Somewhat uncomfortable | 18% | 15% | 18% | 15% |
| Very uncomfortable | 68% | 73% | 68% | 73% |
| Not sure | 4% | 4% | 5% | 4% |
|  | *n=496* | *n=342* | *n=243* | *n=253* |

**Comments:**

* More than four in every five respondents (86%) would be uncomfortable having to see a NDIA-appointed assessor to stay in the NDIS.
* More than two in every three (68%) would be very uncomfortable.
* Almost nine in ten people with disability (88%) and NDIS participants (88%) said that having to see an NDIA-appointed assessor would make them uncomfortable. Almost three-quarters (73%) of each of those cohorts said that this would make them very uncomfortable.
* PWDA members did not differ from the overall sample (86%).

### 1.23 Alignment of the proposed information gathering powers with privacy rights

**Question**: The UNCRPD says people with disability have the right to privacy and to make free choices. How do the NDIA's proposed information gathering powers align with these rights?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Align** | **8%** | **6%** | **8%** | **4%** |
| **TOTAL Conflict** | **86%** | **89%** | **87%** | **91%** |
| Strongly align | 3% | 3% | 3% | 2% |
| Somewhat align | 5% | 3% | 5% | 2% |
| Somewhat conflict | 14% | 13% | 13% | 14% |
| Strongly conflict | 72% | 76% | 74% | 77% |
| Not sure | 6% | 5% | 5% | 5% |
|  | *n=496* | *n=342* | *n=243* | *n=253* |

**Comments:**

* More than four in every five (86%) respondents overall say that the NDIA’s proposed information gathering powers conflict with the UNCRPD rights regarding a right to privacy and to make free choices.
* Almost three-quarters (72%) say that these powers strongly conflict with these rights.
* More than nine in ten (91%) NDIS participants say that these powers conflict with the UNCRPD rights (77% say they strongly conflict).
* People with disability (89%) and PWDA members (87%) are also likely to say these powers conflict with the UNCRPD rights.

### 1.24 Reasonableness of ability to make participants pay back unapproved items

**Question**: How reasonable do you think it is to make participants pay back money spent on unapproved items?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Reasonable** | **31%** | **27%** | **26%** | **26%** |
| **TOTAL: Unreasonable** | **60%** | **64%** | **67%** | **66%** |
| Very reasonable | 10% | 7% | 8% | 5% |
| Somewhat reasonable | 21% | 20% | 18% | 21% |
| Somewhat unreasonable | 26% | 26% | 26% | 25% |
| Very unreasonable | 34% | 38% | 41% | 41% |
| Not sure | 8% | 8% | 7% | 8% |
|  | *n=500* | *n=345* | *n=246* | *n=255* |

**Comments:**

* Six in ten respondents overall (60%) believe it is unreasonable to make participants pay back money spent on unapproved items. This includes more than one in three (34%) who believe it is very unreasonable.
* More than two-thirds of PWDA members (67%) and NDIS participants (66%) specifically believe this is unreasonable.
* 64% of PWDA members believe it is unreasonable.

**Question**. Is there anything else you would like to tell us about this?

The key themes raised (from most to least common) by those who said this was **unreasonable** (the majority) and then responded to this question were:

1. **Lack of clarity** and **confusion** about the **rules**.

Respondents expressed confusion about what qualifies as approved versus unapproved spending. They also highlighted inconsistencies and a lack of clear communication from the NDIS.

1. This **financial penalty** will cause **extreme distress** on those already struggling

Many respondents are concerned about the financial impact of having to repay funds, especially given the already precarious financial situations of many of those on the NDIS.

1. It is **unfair** to **punish** participants for **errors** that **may not be theirs** or may be simple mistakes.

Responses highlight perceived unfairness in holding participants responsible for repayment, especially when errors may originate from plan managers or due to complex guidelines.

1. Concerns about the **parallels** with ‘**robo-debt**’

This includes comments about the emotional distress the robo-debt scheme brought on those that were chased for repayment.

**Quotes**

"The spending rules are so unclear, the systems so complex, and the grey areas so large, that 'misuse' of funding is almost inevitable."

"If I am breaking the law some how then education and support is what I need, not retribution. People will end their lives if hit with roboNDIS debts!!"

"Asking me to pay back money when my plan manager is the one who made a mistake, or because the NDIS is being unreasonable (as they often are) is insane and would likely harm me a lot."

"This makes me feel like they assume I am a criminal. What if they mistakenly decided I have claimed something wrong or if they change their mind."

"The fairness of debt recovery depends on the system. If people have spent funds in good faith - on the understanding that it fits under the rules, they should not be penalised."

Those who said this was **reasonable** added:

* Responsibility and accountability is important – so long as the process is fair with clear guidelines.
* Improved clarity around the rule and transparency about the need to pay back claims should be implemented before this policy is put in place.
* The assessment process (including the skills and knowledge of assessors) must be improved before this policy is implemented.
* The NDIA needs to recognise the need for flexible use of funding.
* The is misuse and rorting of the system by both participants and providers – and this must be stamped out.

### 1.25 Negative impacts of impairment-based classes

**Question**: Do you think impairment-based classes without an understanding of all of person's disabilities and whole of life circumstances could lead to some people missing out on supports they need?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Yes** | **91%** | **92%** | **91%** | **92%** |
| **TOTAL: No** | **6%** | **6%** | **5%** | **6%** |
| Definitely yes | 82% | 85% | 81% | 85% |
| Probably yes | 9% | 7% | 10% | 7% |
| Probably no | 2% | 2% | 2% | 2% |
| Definitely no | 4% | 4% | 3% | 4% |
| Not sure | 3% | 2% | 3% | 2% |
|  | *n=490* | *n=339* | *n=243* | *n=251* |

**Comments:**

* Nine in ten respondents (91%) overall believe that impairment-based classes without an understanding of a person's whole of life circumstances will lead to some people missing out on the supports they need.
* The views of people with disability (92%), PWDA members (91%) and NDIS participants (92%) were consistent with the overall sample.

### 1.26 Opinion on whole of life circumstances being considered

**Question**: Do you think all of a person's disabilities, impairment type and whole of life circumstances should be considered together when decisions are made about their access to the NDIS and plan?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Yes** | **94%** | **95%** | **94%** | **94%** |
| **TOTAL: No** | **3%** | **3%** | **4%** | **5%** |
| Definitely yes | 88% | 91% | 89% | 91% |
| Probably yes | 6% | 4% | 5% | 3% |
| Probably no | 1% | 1% | 2% | 2% |
| Definitely no | 2% | 2% | 2% | 3% |
| Not sure | 3% | 3% | 2% | 2% |
|  | n=489 | n=338 | n=241 | n=250 |

**Comments:**

* 94% - or almost all – respondents believe that all of a person’s disabilities, impairment type and whole of life circumstances should be considered together when considering access to the NDIS.
* This view was consistent across NDIS participants (94%). PWDA members (94%) and people with disability (95%).

### 1.27 Impact on accessing support

**Question**: If your disabilities, impairment type and whole of life circumstances are not considered together when decisions are made about your access to the NDIS or plan, would this make accessing the support you need easier or harder?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| **TOTAL: Easier** | **5%** | **4%** | **5%** | **3%** |
| **TOTAL: Harder** | **88%** | **89%** | **88%** | **90%** |
| Much easier | 3% | 3% | 3% | 1% |
| A bit easier | 2% | 1% | 2% | 2% |
| No difference | 2% | 2% | 2% | 2% |
| A bit harder | 5% | 5% | 5% | 4% |
| Much harder | 83% | 84% | 83% | 86% |
| Not sure | 6% | 6% | 5% | 5% |
|  | *n=487* | *n=339* | *n=241* | *n=249* |

**Comments:**

* Almost nine in every ten (88%) respondents believe that not considering their disabilities, impairment type and whole of life circumstances together would make accessing the supports they need harder. Most (83%) say that not considering all these elements will make accessing the supports they need much harder.
* This view is consistent across people with disability (89%). PWDA members (88%) and NDIS participants (90%).

### 1.28 Personal impact of changes

**Question**: What would it mean for you if changes were made that mean your disabilities, impairment type and whole of life circumstances are not considered together when decisions are made about your access to the NDIS or plan?

The key themes raised (from most to least common) were:

1. **Loss** of **holistic care** and impact on **quality of life**

Respondents are concerned that this change may lead to support that does not adequately address the interconnected nature of their disabilities, thereby significantly reducing their overall quality of life.

1. General concerns about a **reduction in support** and **funding**

There are concerns that these changes will lead to decreased funding in general.

1. **Inadequate understanding** of **individual needs**

Respondents repeated their concern that assessors lack a comprehensive understanding of the complex and unique nature of each individual's disabilities.

**Quotes**

"I would likely not get any support as if properly supported I appear to not have a disability but without that support I quickly become very disabled."

"It would mean I live an uncomfortable, diminished life, with an uncertain future and constant stress and anxiety through that future. It would definitely shorten my life."

"It's ludicrous to not take a whole person approach. Every client needs to be well understood."

"You can’t categorise people in groups if you are funding on a needs basis. You can’t consider a disability in isolation from a persons health, supports, circumstances. Need a holistic approach."

"The impact of multiple disabilities is often more than 1+1+1+1=4. It can be more like 1+1+1+1=8 or 9. Because of our son’s behaviours, the need for personal care, and the need for Auslan, we need to pay a higher rate to get quality staff."

### 1.29 Concern about the impact of these changes on some groups

**Question**: How worried are you that the changes could mean groups of people with disability are treated unfairly?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| **TOTAL: Worried** | **93%** | **96%** | **93%** | **96%** |
| **TOTAL: A little/Not Worried** | **5%** | **3%** | **6%** | **2%** |
| Very worried | **84%** | 88% | 86% | 89% |
| Somewhat worried | **9%** | 8% | 7% | 7% |
| A little worried | **3%** | 2% | 5% | 2% |
| Not at all worried | **2%** | 1% | 1% | - |
| Not sure | **2%** | 1% | 2% | 1% |
|  | *n=492* | *n=341* | *n=244* | *n=252* |

**Comments:**

* More than nine in ten respondents overall (93%) are worried that the changes could mean groups of people with disability are treated unfairly – 84% are very worried.
* NDIS participants (96%) and people with disability (96%) are slightly more likely to be worried. PWDA members (93%) are consistent with the overall sample.

### 1.30 Alignment with UNCRPD rights to equal treatment and non-discrimination

**Question**: The UNCRPD says people with disability have the right to equal treatment and non-discrimination. How well do you think defining and treating people differently based on impairment type without understanding all their disabilities and whole of life circumstances aligns with this right?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Aligns** | **5%** | **2%** | **4%** | **2%** |
| Aligns very well | **2%** | - | 1% | - |
| Aligns pretty well | **3%** | 2% | 3% | 2% |
| **Does not align well** | **89%** | **91%** | **91%** | **92%** |
| Not sure | **6%** | 5% | 4% | 5% |
|  | *n=488* | *n=337* | *n=240* | *n=250* |

**Comments**:

* Almost nine in every ten (89%) respondents overall said that defining and treating people differently based on their impairment type without considering all their disabilities and whole of life circumstances does not align with the UNCRPD rights regarding the right to equal treatment and non-discrimination.
* NDIS participants (92%), PWDA members (91%) and people with disability (91%) were even more likely to say this does not align with the UNCRPD rights.

**Question**. Is there anything else you would like to tell us about this?

The key themes raised (from most to least common) were:

1. **General concerns** about **discrimination** and **inequality**

Respondents are concerned that these changes will lead to increased bias and discrimination, particularly that the introduction of impairment types will lead to stereotyping.

1. General view that the changes **go against the UNCRPD**.

Respondents are concerned that the proposed changes violate these principles and/or represent a ‘backward step’ in relation to these rights.

1. Concerns about the **loss of individualised support**

Respondents again raised concerns about the loss of flexibility and individualised supports, something that is fundamental to the NDIS.

1. Concerns about **future access and treatment**

Respondents are concerned about losing access to supports now or in the future, particularly as they age.

**Quotes**

"Even two people with identical disabilities who live very similar lives have very different needs. Grouping people together creates a lot of bias and assumptions that may not be true."

"The 'classes' of participants is dehumanising, it's a dangerous form of othering. We are not tick boxes, we are people."

"Putting people into categories or grouping them is not inclusive & against our human rights to be individuals."

"Plan should be individualized in terms of goals and then supports funded that assist that person to achieve their goals."

“"This is pitting one group of PWD with another group of PWD. It is a divide and conquer scenario."

### 1.31 Fairness of the proposed NDIS assessment process

**Question**: How fair do you think the proposed process is for assessing who gets access to the NDIS?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| **TOTAL: Fair** | **10%** | **7%** | **11%** | **8%** |
| **TOTAL : Unfair** | **81%** | **86%** | **81%** | **86%** |
| Very fair | 3% | 2% | 3% | 2% |
| Somewhat fair | 7% | 5% | 8% | 6% |
| Somewhat unfair | 8% | 8% | 7% | 8% |
| Very unfair | 73% | 78% | 74% | 78% |
| Not sure | 8% | 7% | 7% | 6% |
|  | n=486 | n=339 | n=240 | n=251 |

**Comments:**

* More than four in every five respondents overall (81%) believe that the proposed changes for assessing who gets access to the NDIS are unfair. Almost three-quarters (73%) believe the changes are very unfair.
* People with disability (86%) and NDIS participants (86%) were even more likely than the overall sample to think these changes are unfair.
* PWDA members were consistent with the overall sample (81%).

### 1.32 Concern about people being excluded from the NDIS

**Question**: How concerned are you that the new access rules could exclude people from the NDIS who need support?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| **TOTAL: Concerned** | **89%** | **91%** | **88%** | **91%** |
| **TOTAL: A little/Not at all concerned** | **7%** | **6%** | **8%** | **6%** |
| Very concerned | **78%** | 82% | 77% | 81% |
| Somewhat concerned | **11%** | 9% | 11% | 10% |
| A little concerned | **5%** | 5% | 6% | 6% |
| Not at all concerned | **2%** | 1% | 2% | - |
| Not sure | **3%** | 2% | 4% | 2% |
|  | *n=486* | *n=339* | *n=240* | *n=250* |

**Comments**:

* Almost nine in ten (89%) respondents are concerned that the new access rules could exclude people from the NDIS who need support. More than three-quarters (78%) are very concerned.
* NDIS participants (91%) and people with disability (91%) are slightly more likely to be concerned, while PWDA members (88%) are slightly less likely (but still highly likely to be concerned).

### 1.33 Ease of demonstrating the need for NDIS supports under the new rules

**Question**: How easy or difficult would it be for you to show you still need NDIS support under the new rules?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| TOTAL: Easy | 19% | 15% | 19% | 14% |
| TOTAL: Difficult | 59% | 61% | 56% | 63% |
| Very easy | 8% | 6% | 9% | 5% |
| Somewhat easy | 11% | 9% | 10% | 9% |
| Somewhat difficult | 24% | 24% | 22% | 27% |
| Very difficult | 35% | 37% | 34% | 36% |
| Not sure | 21% | 24% | 24% | 24% |
|  | n=484 | n=340 | n=241 | n=250 |

**Comments:**

* More than half (59%) of respondents said it would be difficult for them to show they still need NDIS support under the new rules. More than one in three (35%) say it would be very difficult.
* 63% of NDIS participants believe it will be difficult to demonstrate they still need support under the new rule – 36% believe it will be very difficult.
* More than half of people with disability (61%) and PWDA members (56%) believe it will be difficult to show they still need NDIS support under the new rules.

### 1.34 Potential for the proposed changes to violate the right to live independently

**Question**: The UNCRPD says people with disability have the right to supports that let them live independently and be included in the community. Could the NDIA removing a person's access to the NDIS go against this right?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| **TOTAL: Yes** | **93%** | **95%** | **94%** | **95%** |
| **TOTAL: No** | **2%** | **2%** | **2%** | **1%** |
| Definitely yes | 80% | 84% | 83% | 84% |
| Probably yes | 13% | 11% | 11% | 11% |
| Probably no | 1% | 1% | 1% | 1% |
| Definitely no | 1% | 1% | 1% | 0% |
| Not sure | 5% | 3% | 4% | 3% |
|  | *n=486* | *n=339* | *n=240* | *n=249* |

**Comments:**

* More than nine in ten (93%) respondents overall believe that removing access to the NDIS will go against the UNCRPD right for people with disability to have the right supports that let them live independently and be included in the community. 80% of respondents responded to this question with ‘definitely yes’.
* People with disability (95%), NDIS participants (95%) and PWDA members (94%) were even more likely to say that removing access to the NDIS would go against this UNCRPD right.

**Question**: Is there anything else you would like to tell us about this?

The key themes raised (from most to least common) were:

1. General concerns about a **loss of supports**

Respondents are concerned about being removed from the scheme and the impact this will have on their ability to access supports, as well as their wider mental and physical health.

1. Fear of increased **discrimination** and **unfair** treatment.

Respondents feel that the NDIS treats them unfairly, with the goal of removing their supports rather than assisting them.

1. Concerns about **inadequate assessments** and decision-making process.

Participants repeated their concerns about assessors being poorly trained, and lacking knowledge and skills.

**Quotes**

"I am so scared under this bill that I will be removed from NDIS. Without NDIS I will be dead. I cannot do anything physically by myself."

"Taking away support especially when there is not suitable alternative options for support is setting disabled people up for poor life outcomes - poor wellbeing, increased poor health, increased risk of severe poverty and homelessness, increased risk of negative interaction with justice system, increased risk of suicide."

"This is very frightening- NDIS supports are critical for many families."

"Why am I filling in forms to keep proving my disabilities are permanent and will not get better!"

"The NDIA behave like an insurance corporation, their goal is to always remove access to the funding."

"Under the new rules it would be very difficult to show my need for NDIS supports because a random assessor who does not know me could not possibly understand me or my disability."

"It is easy to see our loved one has a disability. It is not so easy to see how complex this disability is."

### 1.35 Confidence in the mainstream system to meet their needs

**Question**: How confident are you that mainstream systems can meet your disability support needs?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| **TOTAL: Confident** | **7%** | **8%** | **8%** | **6%** |
| **TOTAL: Not very/Not at all Confident** | **87%** | **88%** | **88%** | **91%** |
| Very confident | **2%** | 3% | 3% | 2% |
| Somewhat confident | **5%** | 5% | 5% | 4% |
| Not very confident | **19%** | 19% | 20% | 19% |
| Not at all confident | **68%** | 69% | 68% | 72% |
| Not sure | **5%** | 4% | 5% | 3% |
|  | n=483 | n=340 | n=240 | n=250 |

**Comments:**

* Almost nine in ten (87%) are not confident that mainstream systems can meet their disability support needs. More than two in three of these are not at all confident (68%).
* NDIS participants are slightly more likely to not be confident in the ability of mainstream systems to meet their disability support needs (91%), as are people with disability (88%) and PWDA members (88%).

### 1.36 Likelihood of receiving the same level of support

**Question**: How likely is it that you would get the same level of support from a mainstream service, like health, instead of the NDIS?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Likely** | **7%** | **7%** | **9%** | **4%** |
| **TOTAL: Unlikely** | **89%** | **88%** | **85%** | **90%** |
| Very likely | **4%** | 4% | 5% | 2% |
| Somewhat likely | **3%** | 3% | 4% | 2% |
| Somewhat unlikely | **10%** | 9% | 10% | 8% |
| Very unlikely | **79%** | 79% | 75% | 82% |
| Not sure | **6%** | 6% | 6% | 5% |
|  | *n=483* | *n=339* | *n=240* | *n=250* |

**Comments**:

* Almost nine in ten (89%) believe it is unlikely they would get the same level of support from a mainstream service instead of the NDIS. More than three—quarters believe it is very unlikely.
* NDIS participant (90%) and people with disability (88%) were similar in their views, while PWDA members (85%) were slightly less likely to think it is unlikely they would receive the same level of support from mainstream services.

### 1.37 Concerns over Difficulty Accessing Support if Shifted to States/Territories

**Question**: How worried are you that shifting supports out of the NDIS and back to the States and Territories could create gaps and make it harder to get help?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Worried** | **89%** | **91%** | **91%** | **93%** |
| **TOTAL: A little/not at all worried** | **7%** | **6%** | **8%** | **5%** |
| Very worried | **78%** | 81% | 82% | 83% |
| Somewhat worried | **11%** | 10% | 9% | 10% |
| A little worried | **5%** | 5% | 6% | 5% |
| Not at all worried | **2%** | 1% | 2% | - |
| Not sure | **4%** | 2% | 1% | 2% |
|  | *n=484* | *n=339* | *n=239* | *n=250* |

**Comments**:

* Almost nine in ten respondents (89%) are worried that shifting supports out of the NDIS and back to the states/territories will make it harder to get help. More than three-quarters (78%) are very worried about this.
* NDIS participants (93%), PWDA members (91%) and people with disability (91%) are slightly more likely to be worried about this.

### 1.38 Impact on access to the supports they need

**Question**: Based on your current understanding of foundational supports, how do you think their implementation could affect/impact your access to the supports you need?

The key themes raised (from most to least common) were:

* **Reduction** in support **quality** and **accessibility**

Respondents are particularly concerned about ‘gaps’ in the system that will lead to some not receiving the supports they need. There are also concerns about long wait times, inadequate service options and an overall reduction in the supports offered.

* **Inadequate funding** and **preparedness** of the State/Territories

There is clear scepticism about the ability of States/Territories to fund a foundational supports system, and respondents expect such as system to become underfunded and poorly managed as other public services are.

* **Increased** **complexity** and **administrative burden**

Respondents fear that splitting up services will make them difficult to access and will increase the administrative burden on them.

**Quotes**

“Deliberately decentralising supports builds in gaps that people and their varied requirements will fall into, for sure.”

"Long wait times, no choice, few options, inadequate provision."

"The community and mainstream funding would not be able to accommodate the needs of people with disabilities and the amount of people needing this support."

"My support needs are very complex. Foundational supports as described are useful but do not address a majority of my needs."

"The states are all struggling financially now. There is no money left. This is just what politicians do. Shift responsibility in order to shift blame in the long run when it all goes pear shaped."

"We live in a tiny rural village - the likelihood of services being available is none."

"States are notorious for underfunding state services. I have zero confidence they will fund their share equally & non politically."

"A complete nightmare. I'm also terrified that even NDIS participants will have their supports fractured over systems. I cannot cope with that kind of administrative burden."

“State governments are not currently equipped to take over from NDIS. Additionally, this would require disabled people to apply to two different support schemes instead of one, adding undue pressure and stress to people who are already facing additional struggles to that of the able-bodied population.”

### 1.39 Opinion on realistic rollout of foundational supports

**Question**: Do you think the planned rollout of "foundational supports" starting in July 2025 is realistic and well-supported?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **4%** | 4% | 5% | 2% |
| No | **81%** | 85% | 82% | 87% |
| Not sure | **16%** | 11% | 13% | 11% |
|  | *n=483* | *n=339* | *n=239* | *n=249* |

**Comments**:

* More than four in five (81%) believe that the rollout of “foundational supports” in July 2025 is not realistic or well-supported.
* NDIS participants (87%) are more likely to believe the rollout is not realistic or well supported, as are people with disability (85%) and PWDA members (82%).

**Question**: Is there anything else you would like to tell us about this?

Many of the comments related to this question repeated the themes raised in the previous question. The key themes (from most to least common) are listed below:

* Scepticism about whether states can and will fund this – including the view that this is just shifting the expense from one area of government to another.
* Concerns over the adequacy and coverage of State provided foundation supports.
* Lack of details and transparency about the proposed change.
* These changes should be co-designed with people with disability.

**Quotes**

"The ability of the public education sector to provide adequate disability services is virtually non-existent."

"The states needed to have 1) been less thorough in dismantling the old systems 2) agreed to the new system and have it in place before we have to rely on it."

"If you expect the state systems to provide adequate support it needs to be planned for very carefully."

"Any legislative changes need to be co-designed with PWD - a very large group, not just PWD hand-picked by the government and/or who head up disability organisations."

"The States have insufficient capacity to do what they are supposed to do now."

"The state governments are all broke at the moment and so are our health systems."

"Foundational supports also need to be co-designed (genuinely!) and co-produced."

### 1.40 Adequacy of changes to support marginalised groups

**Question**: Do you believe the changes will adequately support marginalised groups, such as First Nations people or those in regional areas?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **8%** | 8% | 9% | 7% |
| No | **67%** | 70% | 65% | 69% |
| Not sure | **25%** | 22% | 22% | 23% |
|  | n=482 | n=339 | n=240 | n=249 |

**Comments:**

* More than two thirds (67%) of respondents believe that the changes will not adequately support marginalised groups.
* This is the view held by 70% of people with disability, 69% of NDIS participants and 65% of PWDA members.

### 1.41 Experience of challenges due to being a marginalised group

**Question**: Have you experienced any specific challenges due to being part of a marginalised group?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participants** |
| Yes | 28% | 30% | 29% | 30% |
| No | 72% | 70% | 71% | 70% |
|  | *n=200* | *n=146* | *n=102* | *n=109* |

**Comments**:

* More than one in four (28%) respondents have experienced specific challenges due to being part of a marginalised group.
* NDIS participants (30%), people with disability (30%) and PWDA members (29%) were all only slightly more likely to have experienced challenges due to being part of a marginalised group.

**Question**: If yes, please tell us about the challenges you have experienced?

The types of challenges respondents face are listed below, in order of the most to least common type of marginalisation.

* **Regional disadvantages and accessibility Issues**

"Living in a regional area has an impact on access to services and service providers. If there is only one provider in the region then we have no other choice."

"Living in a regional area, not have a range of services - need to select from what is available including service offerings."

"Regional areas are severely impacted by thin markets. Wait lists are horrendous and participants are forced to stay with substandard providers due to having no other choices."

* **LGBTIQ+ Discrimination**

"As an LBGTIQA+ person, I've already been discriminated against and treated inappropriately by the NDIS."

"I’m LGBTQI community. It's so hard to get SW who are from the community. It impacts all my services and I’m sick of having to out myself to all service providers to get appropriate supports."

"Finding queer friendly and safe supports, particularly within companies."

* **Disability related discrimination**

"Attitudinal barriers: I am often considered intellectually disabled because I am in a wheelchair."

"Having an invisible disability such as Autism it is often assumed I am not disabled and that I have no difficulty navigating life."

"The NDIS has never been able to cater for psychosocial disability."

* **Racial and or Cultural discrimination**

"I asked an NDIS staff member if they had Aboriginal people on their team I could speak to. They said 'I don't go around asking people about their race, that's discrimination'."

“Racism inability to get good supports.”

"Discriminatory practices against some non-English speaking participants, despite them having excellent advocates, supports etc in place at assessments and reviews. Very evident racism."

* **Gender-based challenges**

"As a woman it takes years longer to receive a diagnosis for chronic illnesses and invisible disabilities."

"My needs as a woman and as a mum have not been addressed. The NDIS desperately needs a gender strategy."

### 1.42 Concern about the impact of stricter rules on flexibility

**Question**: Are you concerned about the stricter rules on how flexible funding can be spent?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **84%** | 86% | 86% | 89% |
| No | **8%** | 6% | 5% | 4% |
| Not sure | **8%** | 8% | 9% | 6% |
|  | *n=481* | *n=338* | *n=237* | *n=248* |

**Comments**:

* More than four in five respondents (84%) are concerned about the stricter rule on how flexible funding can be spent.
* This rises to 89% of NDIS participants, and 86% of both people with disability and PWDA members.

### 1.43 Opinion on the introduction of ‘stated supports’

**Question**: Do you feel that the introduction of "stated supports" adds unnecessary complexity to the funding model?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **78%** | 81% | 84% | 83% |
| No | **9%** | 6% | 6% | 6% |
| Not sure | **13%** | 13% | 10% | 11% |
|  | *n=478* | *n=335* | *n=234* | *n=245* |

**Comments**:

* More than three-quarters (78%) of respondents feel that the introduction of “stated supports” adds unnecessary complexity to the funding model.
* This rises to 84% of PWDA members, 83% of NDIS participants and 81% of people with disability.

**Question**. Is there anything else you would like to tell us about this?

The key themes raised reflected those raised in other questions and are listed below (from most to least common):

* **The changes will lead to decreased flexibility, especially for those whose needs fluctuate.**

"Support needs don’t run like clockwork, we are human, we need to be treated as human beings. We have good days, bad days, and impossible days."

"Disability is very varied if it is made so difficult to use the funding it is just making a mockery of disabled people!"

* **These changes will increase bureaucracy and complexity, making it harder to access the NDIS.**

"It's already very strict. Please don't put even more restrictions on it."

"The system is already complex and overwhelming to navigate. Increasing complexity is going to increase stress."

* **There will be a loss of individual choice and control over supports**.

"I think it's patronising and paternalistic to imagine that the staff at NDIA know what's best for a PWD, in such exacting ways."

"Yet another NDIS way of complicating matters and taking away our right to choice and control of our own support needs."

* **The changes will lead to inefficiency and mismanagement, as the rigid nature of ‘stated supports’ will lead to the inappropriate allocation of funds.**

"The NDIS will only fund the basic of any item - this means the item is usually cheap, not fit for purpose, easily breaks, requires upgrading or replacing regularly."

### 1.44 Importance of people with disability shaping the NDIS

**Question**: How important is it to you that people with disability help shape the NDIS rules and processes?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Extremely/Very Important** | **97%** | **98%** | **98%** | **98%** |
| Extremely important | 92% | 94% | 93% | 94% |
| Very important | 5% | 4% | 5% | 4% |
| Somewhat important | 2% | 1% | 2% | - |
| Not very important | - | - | - | - |
| Not at all important | - | - | - | - |
| Not sure | 1% | 1% | - | 1% |
|  | *n=479* | *n=336* | *n=235* | *n=246* |

**Comments**:

* Almost all (97%) respondents believe that it is extremely or very important that people with disability help shape the NDIS rules and processes. 92% - or more than nine in every ten – believe this is very important.
* People with disability (98%), PWDA members (98%) and NDIS participants (98%) also almost universally help this view.

### 1.45 Trust in government redesigning the NDIS without input from people with disability

**Question**: How much do you trust the government to design the new NDIS in a way that works for you without input from people with disability?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Trust** | **7%** | **8%** | **10%** | **6%** |
| Completely trust | 1% | 1% | 2% | - |
| Mostly trust | 2% | 2% | 3% | 2% |
| Somewhat trust | 4% | 5% | 5% | 4% |
| **Do not trust** | **90%** | **91%** | **90%** | **92%** |
| Not sure | 3% | 1% | 1% | 2% |
|  | *n=480* | *n=337* | *n=236* | *n=247* |

**Comments**:

* 90% of respondents overall do not trust the government to design the new NDIS in a way that works for them, without input from people with disability.
* This was also the view of the vast majority of NDIS participants (92%), people with disability (91%) and PWDA members (90%).

### 1.46 Concern about passing legislation without co-design

**Question**: Do you think there is too much danger in passing the legislation without the rules and assessment tools being written at the same time in a co-design process with people with disability?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **93%** | 93% | 94% | 94% |
| No | **3%** | 2% | 3% | 2% |
| Not sure | **5%** | 4% | 3% | 4% |
|  | n=480 | n=337 | n=236 | n=247 |

**Comments:**

* 93% of respondents overall believe there is too much danger in passing legislation without the rules and assessment tools being written in a co-design process with people with disability.
* This was also the view of PWDA members (94%), NDIS participants (94%) and people with disability (93%).

### 1.47 Support for advocacy funding

**Question**: Do you think there should be guaranteed funding for advocacy to help people with disability engage with NDIS processes?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **95%** | 96% | 97% | 98% |
| No | **2%** | 1% | 1% | 1% |
| Not sure | **3%** | 2% | 3% | 2% |
|  | n=478 | n=335 | n=235 | n=246 |

**Comments**:

* Almost all (95%) respondents believe there should be guaranteed funding for advocacy to help people with disability engage with NDIS processes.
* This view is even more prevalent amongst NDIS participants (98%), PWDA members (97%) and people with disability (96%).

**Question**: Is there anything else you would like to tell us about this?

The key themes raised are listed below (from most to least common):

* **A general belief that advocacy is important and should be enhanced.**

"Advocacy is crucial for people who cannot speak for themselves."

"Advocacy support is a must!!! We need people we can trust, that understand the NDIS and who are on our side to help us navigate the overwhelming planning processes!"

"Advocacy groups need much much more funding."

* **A belief the people with disability should be involved in decision making, and that co-design should be fundamental.**

"All decisions about disabled people should be made with our input. We are the experts about our needs and our lives."

"Disability supports must be co-designed and co-implemented with people with disability to ensure the system works."

"Codesign is vital at each step of decision making."

* **Distrust in the government in general, and belief that they do not have the interests of people with disability as their focus.**

"The government does not have any genuine concern for pwd. I think businesses are looking at ways to get government money through exploitation of pwd."

"Cannot trust the government and this legislation should be scrapped."

"The government sits in those ivory towers light years away from the real world playing god with peoples lives."

* **There should be access to legal and rights-based supports.**

"When I was trying to access NDIS all advocates in my area were defunded. Navigating the system alone was heart breaking."

"I have used an advocate in the past to challenge my plan at the AAT. There is no way I would have been able to effectively represent myself without their help."

"There needs to be better access to legal supports for people with disability or disadvantage through an independent legal body with oversight by the judiciary system."

### 1.48 Importance of the right to challenge NDIA decisions

**Question**: How important is it to you to have clear rights to challenge NDIA decisions you disagree with?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Very/Extremely Important** | **98%** | **99%** | **98%** | **99%** |
| Extremely important | 94% | 95% | 93% | 95% |
| Very important | 4% | 4% | 5% | 4% |
| Somewhat important | 1% | 1% | 2% | 1% |
| Not sure | 1% | 1% | 0% | 0% |
|  | n=477 | n=334 | n=235 | n=246 |

**Comments:**

* Almost all respondents (98%) believe it is either extremely or very important for them to have clear rights to challenge NDIA decisions they disagree with.
* This view is also almost universal amongst NDIS participants (99%), people with disability (99%) and PWDA members (98%).

### 1.49 Concern about accessing independent reviews of decisions

**Question**: How worried are you that the changes will make it harder for you to get an independent review of decisions about your NDIS supports?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Somewhat/Very Worried** | **95%** | **97%** | **96%** | **97%** |
| TOTAL: A little/Not at all Worried | 2% | 2% | 2% | 1% |
| Very worried | 88% | 90% | 89% | 90% |
| Somewhat worried | 7% | 7% | 7% | 7% |
| A little worried | 1% | 1% | 1% | 1% |
| Not at all worried | 1% | 1% | 1% | - |
| Not sure | 3% | 2% | 2% | 2% |
|  | *n=476* | *n=334* | *n=235* | *n=246* |

**Comments**:

* Almost all respondents (95%) are worried that the proposed changes will make it harder for them to get an independent review of decisions about their NDIS supports. 88% - or almost one in nine – are very worried about this.
* NDIS participants and people with disability (both 97%), along with PWDA members (96%) are slightly more likely to be worried about this.

### 1.50 Clarity and strength of the new review and appeal rights

**Question**: Do you think the review and appeal rights in the new NDIS law are clear and strong enough*?*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | 3% | 3% | 4% | 2% |
| No | 80% | 84% | 82% | 85% |
| Not sure | 17% | 13% | 14% | 13% |
|  | n=478 | n=335 | n=236 | n=247 |

**Comments:**

* Four in five respondents (80%) do not believe that the review and appeal right in the new NDIS law are clear and strong enough.
* NDIS participants (85%), people with disability (84%) and PWDA members (82%) are even more likely to believe this.

### 1.51 Confidence in receiving help to navigate the review and appeal process

**Question**: Do you feel confident you would get enough information and help to use the review and appeal process if you needed it?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Confident** | **8%** | **6%** | **7%** | **5%** |
| **TOTAL: Not very/Not at all Confident** | **87%** | **90%** | **89%** | **92%** |
| Very confident | **3%** | 2% | 2% | 1% |
| Somewhat confident | **5%** | 4% | 5% | 4% |
| Not very confident | **17%** | 17% | 17% | 16% |
| Not at all confident | **70%** | 73% | 72% | 76% |
| Not sure | **5%** | 4% | 3% | 3% |
|  | *n=475* | *n=333* | *n=235* | *n=246* |

**Comments**:

* 87% - or almost nine in every ten respondents – are not very or not at all confident that they would get enough information and help to use the review and appeal process.
* This rises to 92% of NDIS participants, 90% of people with disability and 89% of PWDA members.

### 1.52 Overall impact of the changes

**Question**: Do you think the changes overall will make it easier or harder for people with disability to access justice and defend their rights?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| **TOTAL: Easier** | **2%** | **2%** | **2%** | **1%** |
| **TOTAL: Harder** | **90%** | **94%** | **92%** | **95%** |
| Much easier | 1% | 1% | 1% | - |
| A bit easier | 1% | 1% | 1% | 1% |
| No difference | 1% | 1% | 1% | - |
| A bit harder | 8% | 8% | 9% | 8% |
| Much harder | 82% | 86% | 83% | 87% |
| Not sure | 6% | 3% | 4% | 3% |
|  | n=476 | n=334 | n=235 | n=246 |

**Comments:**

* Nine in every ten respondents (90%) believe the changes overall will made it harder for people with disability to access justice and defend their rights. More than four in five (82%) believe it will make this much harder.
* NDIS participants (95%) almost universally believe that these changes will make it harder for people with disability to access justice and defend their right. This is also the view of most people with disability (94%) and PWDA members (92%).

**Question**: Is there anything else you would like to tell us about this?

The key themes raised by participants are listed below (from most to least common):

* **General concerns about a reduction in rights and the appeal process**

"It's already horrifying. The eligibility reassessment team in particular are all about stonewalling, non-communication, providing insufficient information, and playing 'gotcha' games with participants' lives."

"This will disadvantage those who lack the capacity to understand when their human rights are being violated."

"Appalling that any government decision about an individual could be exempt from review."

* **General distrust in NDIA and the Government.**

"The government should look at how much money they are spending on lawyers fighting at Aat and assess whether this amount of money could be used in better ways."

"It is clear that the government does not value disabled people. They see us as an inconvenient expense."

"Government resents any external/independent review of its decision about individuals. it always makes this as difficult as it can.

* **The need for clear and fair review processes.**

"Every step of appeal process needs to be clear and explained according to the person's understanding, including in the style the person needs."

"There needs to be an appeal mechanism where the assessment tool used is not suitable for your disability type."

* **Impact of the changes on accessibility and justice**

"How many people will suffer from poorly designed plans without proper redress??"

"It's this element of blocking reviews is the most concerning. It's like the government is closing out the right to review."

* **Need for advocacy and support.**

"Appropriate funding for advocacy is central to to appealing unfair decisions."

"PWD should be able to keep their public privacy when doing appeals and going to AAT. The current system is hugely flawed and not accessible to PWD."

### 1.53 Changes moving the NDIS to a top-down model

**Question**: Do you feel the proposed changes will move the NDIS towards a more NDIA-controlled, top-down model?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **84%** | 85% | 85% | 87% |
| No | **5%** | 4% | 5% | 5% |
| Not sure | **10%** | 11% | 10% | 8% |
|  | n=459 | n=321 | n=230 | n=236 |

**Comments:**

* More than four in every five respondents (84%) believe that the changes will move the NDIS towards a more NDIA controlled, top-down model.
* This is also the view of 87% of NDIS participants, and 85% of both people with disability and PWDA members.

### 1.54 Opinion on whether the changes align with the original vision of the NDIS

**Question**: Do you think these changes align with the original vision of the NDIS to empower people with disability?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **4%** | 3% | 5% | 3% |
| No | **90%** | 91% | 90% | 92% |
| Not sure | **6%** | 6% | 5% | 6% |
|  | n=458 | n=321 | n=229 | n=236 |

**Comments:**

* Nine in ten respondents (90%) do not believe that these changes align with the original vision of the NDIS to empower people with disability.
* NDIS participants (92%) are slightly more likely to agree with this and are people with disability (91%). PWDA members (90%) are just as likely as the overall sample to hold this view.

### 1.55 Additional concerns about changes

**Question**: Do you have any other concerns or thoughts about the proposed changes to the NDIS?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **People with disability** | **PWDA Member** | **NDIS Participant** |
| Yes | **68%** | 69% | 66% | 70% |
| No | **31%** | 31% | 35% | 30% |
|  | n=397 | n=277 | n=200 | n=205 |

**Comments:**

* The majority of respondents (68%) have further concerns and thoughts about the proposed changes. These are discussed below.

**Question**: If yes please tell us your concerns or thoughts

The key themes raised by participants are listed below (from most to least common):

* **General concerns about a loss of choice and control**

"This will mean the NDIA have 100% control and participants have 0% control."

"We will become the chosen for and controlled if these changes become law."

"The proposed stratification into four levels of provider registration not only threatens to limit our freedom in choosing support."

* Concerns about future government policy and management

"If a labor government will go this far, then I am very worried about the political will and appetite to improve the NDIS."

"We're going backwards. I feel like we're headed back to the medical model."

"I am deeply concerned that people are ‘succeeding’ maybe removed from the NDIS."

* **Funding cuts will lead to inadequate supports**

"I am deeply concerned that the removal of funding will prevent people seeking the support that they need."

"It feels like they are always looking for ways to give us less and less. The support I receive now is nowhere near what I started with."

* **Beaucracy and administration will increase**

"Every review makes the system more complicated, making it more difficult to access."

"NDIA staff are shocking and there is no accountability."

* Distrust of the government (and concern about their intentions)

"I just feel sickened that the Bill was done in secret and without any attempt to involve people with disability."

"These changes are being pushed aggressively, it is an abuse of power, controlling, and paternalistic."

* **Impacts on Human Rights and dignity**

"We are going backwards to a time where people were medicated to the teeth and sat in rooms all day."

"I feel our human rights are being revoked."

* **Fear of regression to older care models**

"This feels like a return to the bad old days of institutions."

"We are going backwards to a time where control over our own lives was minimal."

* **Fraud and mismanagement concerns**

"The proposed changes do not ban dodgy providers from setting up new companies and exploiting more disabled individuals."

"Why are participants being punished with cost cutting and increased government control instead of where the waste really is?"

### Demographics

**Note**: respondents were offered an option to select ‘prefer not to say’. This has not be included and so figure may not add to 100%.

|  |  |  |
| --- | --- | --- |
|  | **TOTAL** | **n=** |
| 18-34 | **17%** | 110 |
| 35-64 | **71%** | 457 |
| 65+ | **9%** | 60 |
| Female | **74%** | 476 |
| Male | **18%** | 115 |
| Non-Binary | **5%** | 32 |
| Transgender | **<1%** | 4 |
| Capital city | **52%** | 331 |
| Regional city or town | **34%** | 220 |
| Rural or remote are | **14%** | 85 |
| Aboriginal and/or Torres Strait Islander | **3%** | 20 |
| Speak a language other than English at home | **10%** | 67 |
|  |  |  |

# Summary of findings – Member consultations

### 1.1 Feedback for Government

**Question**: If you could tell the government the most important thing to get right in the NDIS changes?

Members who responded to this question commented that:

* Choice and control are central tenants of the NDIS and should remain as such.
* The NDIS should consider them as a whole, and not just see them through their primary disability. This includes the need to see all the disabilities that impact on them, and how they interact with (and exacerbate) other disabilities.
* Participants should be able to nominate their primary disability, not have that decided for them by an ‘outside’ expert.
* People with disability should be recognised as being experts in their own disability/ies and the support/s that help them best.
* Co-design – not consultation – is essential and should be fundamental to any further changes.
* The government needs to change it’s thinking around the NDIS and stop seeing it as ‘charity’.
* The government needs to also stop framing people as ‘worthy’ or ‘unworthy’ people with disabilities. The contributions of people with disability who can not work are still valid.
* The proposed changes lack safeguards to ensure people with disability are OK – the focus has been on saving money, and not on implementing the findings of the disability royal commission.
* They are concerned that the NDIS is being ‘unlinked’ from their goals and aspirations.
* Forcing all providers to be registered limits the options to participants – especially when in a crisis, outside their normal area or for those in regional/rural areas where options may be limited.
* The proposed changes place the risk and the workload on participants – a cohort who are already struggling.
* There should be avenues for challenge debt decisions.
* The incorrect claiming of supports may not be a participant’s fault and they should not be penalised for that.
* People may end up too afraid to spend money on approved supports as they will fear a debt.
* Support coordinators should be allowed to help participants – and this person should have legal training.
* The entire Bill is unsuitable and needs to be scraped and started again.

**Quotes**

“I would like for this for the NDIS to consider us as whole people, not just our primary disability and our you know, other things that they don't want to consider because where all of our disabilities and our diagnosis is happen in one body. So we have to be considered in a holistic way.”

“Most of all, co design, because if we don't have actual co design, not consultation, but call it co design, then it's not happening with us.”

“The debt that he might not be the participant's fault.”

“The entire bill is unsuitable and needs to be scrapped and started again. So I am not on board with people saying it's, it'll be okay if they do this, obviously, that they those four items I mentioned, I think just some of the greatest potential harms.”

“Is there going to be any way to oppose or question a debt being raised against a participant. My understanding this, that's also not a reviewable decision.”

“The other thing that concerns me is, again, the there's no respecting that people disability experts in what supports help them the most, and this narrowing, this proposal of narrowing supports, limiting them, changing the removing reasonable and necessary and having the government decide what supports people are allowed to use.”

“All of these changes appear to be about putting all of the load and risk onto participants. . And I think the risk, people who are already have a high level of struggle in their daily lives don't deserve to be threatened with this high level of risk, particularly of debts”

“Scrap the sort of charity mindset, they seem to be fostering, and scrap the binary of like, worthy, and unworthy, disabled person. I firmly believe that everyone should be able to get the support that they need, regardless of whether or not they can work.”

“I feel like what's missing is a lot of, I guess, safeguarding and making sure people are doing well. And whether they're safe, I guess there's been I feel like a lot of the conversation around this bill has been about are we saving money and that sort of thing.”

“There seems to be an unlinking of NDIS funding with our goals and aspirations. And I think that's problematic. We shouldn't just be grateful for existing, you know, we're supposed to be thriving. That's what NDIS was meant to be about.”

“Do not force service providers to be registered. This will mean we can’t use non disability specific providers to fix wheelchairs, or we can’t use services in remote areas or while we are travelling.”

### 1.2 Suggested Improvements to the NDIS

**Question**: How could the NDIS changes be improved to better respect the rights of people with disability?

Members who responded to this question commented that:

* Again, co-design is critical.
* Disability is complex, and people with disability can not be ‘put into boxes’. Understanding the interaction of disabilities within one person is critical to providing adequate supports.
* There needs to be clear and powerful pathways for challenging government decisions in relation to the support/s or funding they receive (and there are concerns that the current changes are weakening these).
* More weight should be given to the opinions of people with disability in relation to their own supports – people with disability should be believed when they share their experiences, and the views of ‘professionals’ should not be considered more worthy.
* The NDIS should reflect the original principles it was founded on.

**Quotes**

“I can think of is codesign. Again, um, as well as just getting rid of all of the paternalism with all we know what's best for you. Because obviously, disability is complex. And putting us into boxes doesn't work, especially when we have multiple disabilities that interact with each other.”

“I think it's really important with the proposed changes that there's a right of recourse that when the government gets it wrong, or when the government decides to make a judgment, that we actually have the right to say, well, actually no, for these reasons, and be able to state our case. I think that's really important. And I feel like this proposed legislation is downplaying or diminishing our right to to be able to question the judgments of the government in our own lives.”

“Go back to principles on which NDIS was launched.”

“I think there needs to be a bigger focus on believing disabled people, when they say this is my life. This is the way I struggled, not relied so much on so called professionals, especially professionals who may not know the person directly and have worked with them for a long time.”

“Valuing lived experience over rules and 'experts'”

“Making NDIS 'cost blowout' less of a priority, such that the human rights of people with disabilities are the highest priority for scheme performance and evaluation (especially self-determination)”

“Believe us when we tell the NDIS what we need. We waste so much money telling OTs the exact same thing for them to be believed over us. It is gaslighting”

### 1.3 Options to challenge a needs based assessment

**Question**: What options do you think participants should have to challenge a needs assessment decision before it is sent to the Administrative Appeals Tribunal?

Members who responded to this question commented that:

* Articulating the ways in which disability affects their life and advocating for support/s and funding can be difficult.
* The NDIS should consider that the needs of people with disability can fluctuate dramatically, and that this should be taken into account when considering the support/s and funding they need.
* The onus should not be on them, there should instead be a properly trained workforce who can accurately assess them.
* Again, co-design is important – if the assessment tools were co-designed with people with disability there wouldn’t be such a need to challenge decisions.
* The process should focus more on trust, and less on being adversarial.
* There is no one assessment that can capture the needs of all people with disability – if the assessments were better people wouldn’t need to challenge them.
* Participants need to be fully informed of the decisions made by the NDIA in order to challenge them.
* The proposed Bill is ‘broken’ and should be withdrawn (rather than amendments made).

**Quotes**

”I struggled to articulate the many ways my disability affects my life.”

“The thing I really worried about with the needs assessment is the changeability of our experiences with disability over our life course. So sometimes, I'm an autistic person, I'm level two, which means I require substantial support. I'm highly functional until I'm completely not functional. And that depends on where I am in life.”

“We should be encouraging the NDIS to have planners and a workforce that is trained to evaluate our needs better, I guess. So we don't get to the point where we're having to challenge a needs assessment, I think that that piece of work needs to be done.”

“I think it comes back to code design. If those tools are designed properly, and they are designed with people with disabilities, it might not end up getting to where people have to challenge those decisions.”

“There is no one assessment that can assess all disabilities”

“One of the recommendations in the NDIS review, which is that the NDIS takes a trust-based approach in believing and working with participants, rather than adversarial.”

“We should be able to collaborate and discuss meaningfully with the NDIS/NDIA. the process should be collaborative rather than adversarial.”

### 1.4 Options to challenge a needs based assessment

**Question**: How could the process to challenge a needs assessment work?

Members who responded to this question commented that:

* The assessment should not be a point in time assessment, nor should it be undertaken by someone the NDIA appoints (it should be someone who works with and knows the person with disability).
* It is difficult to comment on the needs assessment without understanding how it will work – they need this information before they can provide feedback.
* The needs assessment does not seem to be trauma informed, and being unable to choose your assessor or work with someone who knows you can be triggering for some people (especially those who have experienced medical trauma previously).
* Having someone you don’t know in your home undertaking an assessment can also pose a safety risk to people with disability – and this needs to be considered, not just how to save the scheme money.
* Having the assessment undertaken by someone they don’t know can cause them to also provide inaccurate information.
* The 90-day timeframe for requesting additional information is not feasible – it takes far longer than that to get in to see a specialist.
* Again, the needs of people with disability fluctuate over time.

**Quotes**

“The way they're proposing it's being done is that someone from the NDIA someone that they choose. Will be doing this point in time assessment that doesn't exist yet. That's just going to create problems. It should always be with us that collaborative thing it should be by people who work with us to know us it shouldn't be a point in time assessment and certainly not with a instrument that hasn't been peer designed”

“We have no two days look the same. So, it will be difficult, and it will be hard to know how that will look like on what day is this assessment going to be done? Can you reschedule this assessment? So, it's difficult to agree or disagree with it without knowing a little bit more about what the needs assessment will look like?”

“It's so hard to know what this assessment will look like. But I know for someone like myself, if I was to have a assessor who I picked, for me, someone who I don't know, come in and assess me, that would be very, very triggering. And it would either, like cause a crisis, or I would just straight up refuse and just not have helped because I don't think this process is very trauma informed, especially. I think for a lot of people, we've been through so many things, we're ok, here's your doctor, you don't get to choose and then that doctors a horrible person, things like that”.

“A lot of emphasis is being put on cutting costs. And on the money aspect of things, nothing is being put on the safety of participants. And I think that's a really big one of this is someone that will be coming potentially into your home into your into your inner bubble, and this is someone that you haven't selected”

“The idea of having someone coming into my home. I don't know assessing me is really terrifying”.

“You should be able to have someone like your support coordinator or an advocate to help you through the process”.

“For anyone with a history of trauma or abuse? This process is neither safe nor accessible.”

“Agree when I'm interacting with people I don't know. I'm not able to express my needs. It'll say the opposite of what I mean. The assessments need to be done by regular therapists.”

“That’s not going to actually even be possible to get a referral from a general practitioner, and get to the top of a specialist waiting list in 90 days, heaven forbid, if you happen to be sick, or unwell or in the middle of a disability related notes are able to function time and deal with the NDIS”

“This seems to have been designed by someone who's never needed to make an appointment with a specialist to fill out a form or do an assessment.”

### 1.5 NDIS Participant budget process

**Question**: What do you think a good NDIS participant budget process would look like?

Members who responded to this question commented that:

* Budgets need to be able to be used flexibly.
* Budgets need to reflect, support and fund the recommendations of the allied health team that work with them.
* Their budget should be available to them in full – not in ‘three month’ allocations. People with disability sometimes need to ‘save’ their budget for larger expenditure or require more intensive supports at different times of the year.
* Key to the above is the NDIS understanding the fluctuating nature of their disability/ies.
* Plan assessors should be adequately trained.
* Navigating the NDIS is challenging in general.
* There should be co-design around the rules.
* Although the wording says that participants will be able to spend their funding more broadly, there is no evidence of this.
* Participants should be educated about the options available to them and then provided with choice about how their budget is managed.

**Quotes**

“I would like to see a budget with more flexibility, and one that supports the recommendations and needs assessments of our sorry, medical and allied health professionals”.

“I would also like to see that there is no drop the budget in chunks or parts. So like a three monthly allocation of the budget, that if you don't use it in the three months, then it goes away. And that will really disadvantage people who banking some of their budget because they've got something bigger coming up, or people who are affected seasonally by different things and need to have like the budget district distribution, like more heavily weighing at a different time of the year to another time.”

“Co-design on the rules. Qualified allied heath professional’s should be onboard reading and assisting planners to understand every individual’s disability. Sack the biased bully planners ndis have now. Keep self-managed”

“I was just thinking about some of the things you were saying in this we keep hearing that spending will be what was. I'm trying to think of the phrase again, but you'll be able to spend more broadly, or something. But I just see no evidence of that.”

“I think what needs to be done is this is changes the education program before they implemented and then give people the choice.”

“I'm not sure what the best way to go about it would be but a way to put the NDIA to understand when we put some funds aside, for example, when I'm in a crisis, I need much more support.”

“I know for myself, I study as well. So during the time that I study, I use more support workers and I use a lot more of my plan than when I'm on break away from uni. So that flexibility would be really good.”

“I don't think there's anyone under the sun that would say, trying to navigate the NDIS is a cakewalk. It's a very huge challenge. And certainly a lot of people with disabilities, a lot of our members, a lot of people have come across to say the same thing.”

“I think the process needs to be flexible and understanding of how variable disability can be.”

“The participant should be in the drivers seat. they know when and how their budget needs to spent. “

### 1.6 Alternatives to the proposed budget system

**Question**: So what alternatives to the proposed participant budget model would work better so people with disabilities don't lose supports?

Members who responded to this question commented that:

* They would like flexibility in how their budget is allocated – some might like 3 monthly allocations while others might like access to their entire budget annually.
* There needs to be greater clarity about what their budget can be used form to ensure they are spending it correctly. This requires greater education.
* The NDIS should be moving towards a fully flexible budgeting and allocation system, where participants have full autonomy – not a more restrictive model.
* There needs to be a quick internal review model, but also a pathway for escalating reviews.

**Quotes**

“I guess maybe if there were different ways of doing the budget that people could choose from. So that there could be that flexibility, like some people maybe need their budget in small chunks, whereas others might need the whole year plus a bit extra for when things get bad, I guess, being able to choose more about how the budget is applied”.

“I think, more clarity around how to use it and support around using it. That would be I think that's one of the really, more important things because some of the amendments, you know, participants potentially having to refund if they don't use their funds properly. So more education around how to use that funding.”

“Maybe having an intermediary, whilst it can be government or extremely independent, independent, will be amazing, but yeah, maybe being able to send things to the ombudsman, because the internal review still is done by the NDIA.”

### 1.7 Safeguards

**Question**: What safeguards should be in place to minimise the likelihood a participant will breach rules around how NDIS plan funds can be spent?

Members who responded to this question commented that:

* Therapists and other allied health professionals should be adequately trained and informed about what is allowed – so as they can advice their clients appropriately.
* There needs to be a consistent approach.
* The system should educate, inform and work with participants – not be adversarial and try to ‘catch them out’.
* There is a heavy focus on participants, but not on providers who market inappropriate supports to them.

**Quotes**

“I was actually in the situation where I had made some purchases that I had an OT recommended and gave me a letter of support for so then in my plan review, I was told that No, I shouldn't have made those purchases. And that it was it was wrong and blah, blah, blah, anyway, you should be able to feel quite confident that if your OT is recommending them and giving you a letter of support that actually it's a legitimate purchase.”

“I think consistency is a key thing that needs to be underpinned.”

“Again, it comes back to that adversarial, us versus them approach and I think it needs to change. So why did this happen? And how can we work together to prevent this”.

“I think there's a lot of crap about how participants are using funds, but not a lot about how providers are using funds, how they are marketing themselves and that sort of thing. And I think, before we get so upset about these participants, we need to be also looking at the people who are getting the money in the end and how they're using those funds. Because I know this stuff, like how much more expensive it is to see a psychologist through NDIS funding compared to a mental health plan, stuff like that.”

“I was thinking a lot of this comes back to like, educating participants, as well as providers.”

“The approach needs to be ‘what is happening and how can we work collaboratively to help you’ rather than ‘you breached rules you will be punished.”

### 1.8 Additional Comments

Members who had final comments stated that:

* They believe that the government should be moving towards a disability rights act.
* The believe in the NDIS, and understand it may need to be changed, but there should be a focus on ensuring it meets its original goals.
* Participants are being forced to take on huge risks in order to access the scheme.
* There are not enough advocacy rights and supports for people with disability.

“I really want to see the NDIS thrive, but I want it to be empowering and codesigned. We deserve to choose our lives.

“Do I assume that risk which I don't have the capacity to understand, protect myself and risk manage, or do I withdraw from the scheme? But the reality is, if I withdraw from the scheme, I have no support, and I will die like that is the real reality that seems to be lost.”

“The other issue is, ordinary citizens in Australia have a whole range of legal protections. If you're a criminal, you have a right to legal representation, you have a right to be heard, you have a whole series of that protect you as a criminal, but as a person with disability who theoretically has rights, legal rights, we seem to have nothing, and there is bugger all advocacy services available to help people to assert their rights, and this bill seems to be stripping away even more of those rights.”

People with Disability Australia (PWDA) is a national disability rights and advocacy organisation made up of, and led by, people with disability.

For individual advocacy support contact PWDAbetween 9 am and 5 pm (AEST/AEDT) Monday to Friday via phone (toll free) on **1800 843 929** or via email at

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