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# Here to Stay

# Working to future proof the NDIS

Member Engagement Summary Report

MAY

2024

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*Here to Stay – Working to future proof the NDIS: 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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# Introduction

People with Disability Australia (PWDA) has a national membership of people with disability. Many of our member were pivotal in establishing the National Disability Insurance Scheme (NDIS). This report has been developed in the context of proposed changes to the NDIS, following the Independent Review of the NDIS. PWDA proudly presents the views of our members in this report.

This report explicitly responds to the Senate Community Affairs Legislation Committee Inquiry into the Exposure Draft of the *National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No.1) Bill 2024* and the ongoing work of the NDIS Provider and Worker Registration Taskforce chaired by Ms Natalie Wade.

PWDA has extensively engaged with its national membership to help shape our responses. We surveyed our membership and received 259 responses, and through two dedicated membership consultations we also consulted with 61 people from the disability community.

We trust the insights and information contained in this report provides further guidance in the ongoing conversations about the NDIS.

# Key insights

**Insight 1 –** Two in three (66%) members believe the NDIA should have visibility of who provides services under the NDIS.

* Members in the consultation argued that this visibility already exists in the form of ABNs, and that it should be mandatory that these are provided to the NDIA.
* Others in the consultations argued that greater transparency for participants was more vital and could be facilitated by a service (website) to rate and review providers or support workers.

**Insight 2 –** Overall, the majority (56%) of members believe all NDIS service providers should not be registered. This rises to 63% of NDIS participants.

* In the consultations some commented that they purposefully don’t use registered providers to allow them to have greater flexibility and autonomy over how their supports are delivered.
* Most members (82%) do however believe that there are situations when service providers should be registered. These situations varied between members but include:
* Vulnerable participants, particularly those unable to advocate for themselves.
* Accommodation providers in general, or like services in ‘closed environments’
* Services that provide direct or personal care
* Large organisations
* Organisations using restrictive practices
* Medical or mental health providers

**Insight 3 –** 81% of NDIS participants want the ability to screen NDIS providers and workers themselves.

* NDIS participants already undertake screening of support workers or providers including:
* Ensuring police checks and WWVP cards are in place
* Undertaking interviews, reference checks and trial periods
* Checking online reviews and/or community feedback and recommendations
* Checking basic business or personal information such as ABNs, insurances, first aid certificate and training.

**Insight 4 –** 65% of members (including 69% of NDIS participants) said they would know what to do if they had safety concerns about a service provider or worker.

**Insight 5 –** Members are clearly concerned about the potential loss of access to services or supports as a result of the proposed changes to NDIS service provider registration.

* 89% of members, and 93% of NDIS participants reported at least one worry about a loss of supports due to the changes to the NDIS service provider registration.
* Amongst NDIS participants the two most common concerns were:

1. It will be harder to get supports (73%)
2. It will be harder to use my funds to get things that work for me (71%)

* This was followed by concern that supports they rely on will no longer be available to them (67%) or that it will be harder to manage on their NDIS plan (41%).
* In the consultations, most (79%) said they were worried that one or more of the supports they rely on could be deemed ineligible for funding under the changes. Most felt that if these were no longer covered they would have no ‘alternatives’ or options to replace them.
* Members in the consultations were also clearly concerned about the curtailing of their choice in what supports best suited them, and acknowledged that without the flexibility to employ non-registered support workers many of the supports they currently receive would not be available to them.

**Insight 6 –** Members in the consultations identified funding for advocacy supports as a gap in the proposed Bill.

**Insight 7 –** Members are unclear on how long a reform process should take.

* When prompted most members did not select a time frame for the changes to registration, and instead selected ‘other’, with most commenting ‘never’ or ‘delay as long as possible’.
* ‘Two years’ was the most commonly selected from the options provided (26%) and as the longest timeframe was most likely a proxy for ‘as long as possible’.

**Insight 8 –** Almost half (49%) of members believe there are situations where the NDIA should cancel someone’s plan or decide how that plan is managed.

* This rises only slightly to 50% of NDIS participants.
* The most common reasons for cancelation or takeover of a plan are clear instances of fraud and/or the mismanagement of funds or where the participant has lost the capacity to self- manage.
* Members believe however that such action should not be taken without communication and consultation from the NDIA. Specifically, participants should be warned and educated prior to having their plan cancelled or taken over. Participants should also have the right to appeal to decision to an independent party.

**Insight 9 –** Members commonly believe that NDIS funds should be able to be used on proposed ineligible items.

* Most commonly, more than half believe participants should be able to use funds to buy:
  + Household appliances (71%)
  + White goods (65%)
  + Holidays (65%)
* A significant proportion also believe that utility bills (48%), groceries (29%) and cosmetics (21%) should be allowed.
* Just one in ten (10%) believe perfume should be allowed.
* These views were reflected in the consultations. For members, household appliances can promote independence (and save money) as they can undertake tasks they may have had to use a support worker for (if the appliance is accessible, for example a benchtop dishwasher).
* There are also concerns that ‘holidays’ might capture respite, something they considered highly important.

**Insight 10 –** Almost all (96%) members believe that people should be able to have NDIA decisions reviewed.

* This rises to 97% of NDIS participants.
* More than eight in every ten members believes that an NDIA review should be fair (90%), easy to access (88%), easy to navigate (86%) and fee (85%). Almost as many (78%) believe it should be quick.

**Insight 11 –** Almost half of members disagreed with the change to needs-based funding.

* This was primarily due to a belief that no ‘tool’ would be able to accurately assess the needs of all people with disability.

**Insight 12 –** Just over half of both members (56%) and NDIS participants (55%) support the proposal **to** extend NDIS plan to a five-year timeframe.

* The largest proportion of both members and NDIS participants (both 46%) believes that NDIS plans should go for five or more years.

**Insight 13 –** A very large majority (87%) of members believe NDIS plan budgets should increase in line with CPI.

* This rises to 88% of NDIS participants.

**Insight 14 –** When being assessed, participants believe the following are important for the NDIA to know:

* Understand the individual, including their life previous to disability, their personal circumstances and goals. Understand the capacity and needs can fluctuate.
* Review and believe the evidence provided by health professionals or participants themselves.
* Understand and accommodate barriers to access such as language or finances.
* Understand the wider implications of disability, especially on families and caregivers.
* Understand the need for stability of supports for people with disability.

**Insight 15 –** Members unanimously disagree with the proposed changes to Housing and Living Supports.

* Members see this change as taking a one-size fits all approach.
* They believe this change will undermines the choice and control that is a central pillar to the NDIS and are vehemently opposed to its introduction.

# Summary of findings – Member survey

### NDIA provider visibility

**Question:** Do you think the National Disability Insurance Agency (NDIA) should have visibility of who provides services under the NDIS?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with disability** |
| Yes | 66% | 62% | 78% | 65% |
| No | 15% | 20% | 3% | 17% |
| Not Sure | 18% | 19% | 18% | 18% |
|  | *n=227* | *n=167* | *n=60* | *n=204* |

**Comments:**

* Two in three (66%) members believe the NDIA should have visibility of who provides services under the NDIS.
* NDIS participants (62%) were only slightly less likely to agree with this, while people with disability did not differ significantly from the total (65%).

### Registration of all NDIS providers

**Question:** Do you think all NDIS service providers should be registered?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with disability** |
| Yes | 34% | 28% | 51% | 33% |
| No | 56% | 63% | 37% | 57% |
| Not Sure | 10% | 10% | 12% | 10% |
|  | *n=225* | *n=167* | *n=59* | *n=202* |

**Comments:**

* Overall, the majority (56%) of members believe all NDIS service providers should not be registered.
* However, the views of NDIS participants and Non-NDIS participants differ significantly. While the majority of NDIS participants (63%) believe service providers should not have to register, the majority of non-NDIS members believe they should (51%).

### Registration of some NDIS providers

**Question:** Do you believe there are situations where some NDIS service providers should be registered?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with disability** |
| Yes | 82% | 84% | 75% | 83% |
| No | 8% | 7% | 12% | 7% |
| Not Sure | 10% | 9% | 14% | 10% |
|  | *n=225* | *n=166* | *n=59* | *n=202* |

**Comments:**

* Most (82%) believe that there are situations where some NDIS service providers should be registered.
* This belief is high across all key cohorts, including 84% of NDIS participants, 75% of non-NDIS participants and 83% of people with disability.
* Additionally, 81% of those who had said not all service providers should be registered (n=127) believe that there are situations where some service providers should be.

The primary situations in which members felt a support worker should be registered included:

* **Vulnerable NDIS participants**, especially those unable to advocate or communicate for themselves.
* **Accommodation providers** including SDA, SIL, group home providers or like services in a ‘closed environment’.
* Services that **provide direct or personal care** to people with disability, especially if one on one inside a home.
* In **large organisations** employing multiple people or providing various supports.
* In circumstances where **restrictive practices** are in use.
* **Medica**l, mental health or therapy supports.

A number of members also stated that all providers should be registered.

### Ability to screen providers

**Question:** Do you want to be able to screen your NDIS providers and workers yourself?

|  |  |  |
| --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** |
| Yes | 80% | 81% |
| No | 8% | 7% |
| Not Sure | 12% | 12% |
|  | *n=224* | *n=165* |

**Comments:**

* 81% of NDIS participants want the ability to screen NDIS providers and workers themselves.
* 12% are not sure, while 7% said they do not want this ability.

Common steps taken to screen providers or support workers included:

* Police checks and/or working with vulnerable people card
* Reference checks
* Interview process
* Trial periods/trial shifts
* Online reviews, community feedback and recommendations
* Checking for basic business or personal information such as ABN, insurances, first aid certificate, qualifications and training.

Other ways in which members screen their providers and support workers include help from their support coordinator, checking social media and reviewing their ‘life experience’.

### Concerns about NDIS service providers

**Question:** If you had a safety concern about a NDIS service provider or worker would you know what to do?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with**  **disability** |
| Yes | 65% | 69% | 53% | 63% |
| Sometimes | 17% | 17% | 18% | 18% |
| No | 18% | 15% | 29% | 20% |
|  | *n=181* | *n=163* | *n=55* | *n=198* |

**Comments:**

* Across the PWDA membership, an average of 65% of people said they would know what to do if they had safety concerns about a service provider or worker.
* More than two in every three (69%) of NDIS participants said that they would know what to do if they had safety concerns about a provider or worker. A further 17% said they would ‘sometimes’ know what to do.
* Over half (53%) of non-NDIS participants said that they would know what to do.

### Reasons for concern relating to provider registration

**Question:** What worries you about the proposed changes to NDIS service provider registration?

|  |  |  |
| --- | --- | --- |
|  | **TOTAL** | **NDIS**  **Participants** |
| It will be harder to get supports | 69% | 73% |
| It will be harder to use my funds to get things that work for me | 64% | 71% |
| Supports I rely on will no longer be available to me | 58% | 67% |
| It will be harder to manage my NDIS plan | 41% | 47% |
| Other (please specify) | 37% | 42% |
| None of the above | 11% | 7% |
|  | *n=218* | *n=163* |

**Comments:**

* 89% of members, and 93% of NDIS participants reported at least one worry about the changes to the NDIS service provider registration.
* Amongst NDIS participants the two most common concerns were:
  + It will be harder to get supports (73%)
  + It will be harder to use my funds to get things that work for me (71%)
* More than two in every three NDSI participants are also concerned that supports they rely on will no longer be available to them (67%).
* Almost half (47%) are worried that it will be harder to manage their NDIS plan

Other concerns not listed here but mentioned by NDIS participants include:

* A loss of control and choice
* A potential increase in costs
* Requirement to disclose their disability when using mainstream services Service quality and availability (as they will be forced to use larger organisations)
* Limited options in regional and rural areas

### Timeline for introducing changes

**Question:** If there are changes to registration, how soon should they happen?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with disability** |
| Six months | 13% | 10% | 23% | 14% |
| One year | 23% | 21% | 29% | 23% |
| Two years | 26% | 27% | 25% | 24% |
| Other | 37% | 42% | 23% | 39% |
|  | *n=216* | *n=160* | *n=56* | *n=193* |

**Comments:**

* The most commonly selected option for members was ‘other’ (37%). This was primarily people saying ‘never’ or calling for a significant delay. This is an estimated one quarter of the overall sample
* Additionally, those who selected other but didn’t say ‘never’ commonly called for greater consultation, PWDA to advocate for a delayed time frame or generally raised concerns about the impacts of these changes.
* Besides ‘other’, the next largest proportion of members would like the changes to happen in two years (arguably a proxy for ‘delay as long as possible’ as this was the longest time frame offered).
* Amongst NDIS participants ‘other’ (42%) was also the most commonly selected response – most of whom again said that the changes should be delayed or never happen. This view was held by around 28% of NDIS participants (the most common).

### NDIA cancelation or take-over of plans

**Question:** Are there situations where the NDIA should cancel someone's plan or decide how their plan is managed?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with**  **disability** |
| Yes | 49% | 50% | 46% | 48% |
| No | 28% | 27% | 29% | 28% |
| Not Sure | 24% | 23% | 25% | 24% |
|  | *n=203* | *n=151* | *n=52* | *n=185* |

**Comments:**

* Almost half (49%) of members believe there are situations where the NDIA should cancel someone’s plan or decide how that plan is managed.
* This rises only slightly to 50% of NDIS participants.

Common justifications for NDIA cancelation or takeover of a plan included:

* **Fraud, or the mismanagement of funds.** This was by far the most common justification and was raised by the majority of participants. This included both fraud by the participant, and exploitation by providers and/or family members.
* **Loss of capacity to manage their funds.** Some participants may need to move to plan- managed if they have lost the ability to self-manage.

Members however stress the need to for consultation and negotiation through-out this process.

Protections and steps to be taken before the NDIA cancels or takes over a plan include:

* **Communication and consultation.** NDIS participants must be given clear and advanced notification of the reasons for the change to or cancelation of their plans, and be given adequate time to respond. Decisions should be made in consultation with the participant. If there are cases of misuse of funds, warnings and education should come before cancelation.
* **Review and appeal mechanisms:** Participants should have the ability to appeal any decision, and decisions should be reviewed by independent parties.

Others simply stated that it should not be up to the NDIA to cancel or takeover anyone’s plan.

### Proposed ineligible uses of NDIS funds

**Question:** Which of the following items do you think people should be able to use their NDIS funds for? Select all that apply.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with**  **disability** |
| Household appliances | 71% | 73% | 72% | 72% |
| White goods | 65% | 67% | 67% | 68% |
| Holidays | 56% | 58% | 54% | 54% |
| Utility bills | 48% | 45% | 64% | 48% |
| Groceries | 29% | 29% | 33% | 29% |
| Cosmetics | 21% | 23% | 19% | 23% |
| Perfume | 10% | 10% | 14% | 11% |
|  | *n=105* | *n=109* | *n=36* | *n=136* |

**Comments:**

* More than seven in ten (71%) members believe that people should be able to use their NDIS funds on household appliances. This rises to 73% of NDIS participants.
* Almost two in three (65%) believe they should be able to use their funds for white goods. This rises to 67% of NDIS participants.
* More than half (56%) believe they should be able to use their funds on holidays. This rises to 58% of NDIS participants.
* Almost half (48%) of members believe NDIS funds should be able to be used on utility bills, although slightly less NDIS participants hold this view (45%).
* 29% of both members in general and NDIS participants believe that funds should be able to be used on groceries.
* More than one in five of both members in general (21%) and NDIS participants (23%) believe they should be able to spend funds on cosmetics.
* 10% of both member and NDIS participants believe they should be able to spend funds on perfume.

### Review of NDIA decisions

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with disability** |
| Yes | 96% | 97% | 90% | 96% |
| No | 1% | - | 4% | 1% |
| Not Sure | 3% | 3% | 6% | 3% |
|  | *n=202* | *n=151* | *n=51* | *n=185* |

**Question:** Do you believe people should be able to have NDIA decisions reviewed?

**Comments:**

* Almost all (96%) members believe that people should be able to have NDIA decisions reviewed.
* This rises to 97% of NDIS participants. No NDIS participants said that people should not have a review option (3% selected not sure).

### Review process

**Question:** How an NDIA decisions is reviewed and appealed should be (select all that apply)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with disability** |
| Fair | 90% | 93% | 83% | 90% |
| Easy to access | 88% | 89% | 85% | 88% |
| Easy to navigate | 86% | 87% | 85% | 86% |
| Free | 85% | 87% | 77% | 86% |
| Quick | 78% | 82% | 67% | 79% |
| Other | 29% | 39% | 29% | 32% |
|  | *n=202* | *n=150* | *n=51* | *n=185* |

**Comments:**

* More than eight in every ten members believes that an NDIA review should be:
  + Fair (90%)
  + Easy to access (88%)
  + easy to navigate (86%)
  + Free (85%)
* Almost as many (78%) believe it should be quick.
* NDIS participants were slightly more likely than member in general to select each of the items.

Those who selected other also commonly suggested:

* Access to an independent advocate or support
* Legal representation (if requested)
* Accessibility considerations (i.e. allowing the participant to interact with the NDIA in a way that meets their accessibility needs).
* The reviewer should be independent and impartial

### Plan length

**Question:** How long do you think a NDIS plan go for?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with disability** |
| One year | 12% | 11% | 16% | 12% |
| Two years | 24% | 23% | 24% | 24% |
| Three years | 16% | 19% | 16% | 16% |
| Four years | 2% | 1% | 4% | 2% |
| Five years | 27% | 28% | 25% | 27% |
| More than five years | 19% | 18% | 16% | 19% |
|  | *n=202* | *n=145* | *n=51* | *n=178* |

**Comments:**

* The largest proportion of both members and NDIS participants (both 46%) believes that NDIS plans should go for five or more years.
* A large proportion of both members (36%) and NDIS participants (34%) believe they should go for two or less years.

### Five-year NDIS plans

**Question:** The Bill proposes a longer five-year timeframe for NDIS plans. Do you support this proposal?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **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’.

### NDIS plans keeping with CPI

**Question:** Do you think NDIS plan budgets should increase with CPI (the Consumer Price Index)?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **TOTAL** | **NDIS Participants** | **Non-NDIS** | **People with disability** |
| Yes | 87% | 88% | 84% | 89% |
| No | 3% | 3% | 6% | 4% |
| Not Sure | 9% | 9% | 10% | 8% |
|  | *n=202* | *n=151* | *n=51* | *n=184* |

**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.

### Information for assessments

**Question:** When your needs are being assessed what do you think is important for the NDIA to know?

The key theme in relation to this question was:

* **Understanding the individual:** this includes their life previously (to measure the impact their disability has had), consideration of their personal circumstance and goals. Assessors need to be experienced and knowledgeable, and be able to understand fluctuations in their capacity and therefore need. Undertake the assessment holistically, and consider the whole person and their environment.

Other themes included:

* **Review (and believe) the evidence:** members stress that assessors need to listen to and believe NDIS participants and their caregivers. They need to read and consider the reports provided by professionals. There is also opposition to repeatedly having to undergo assessments for permeant disabilities.
* **Understand and accommodate barriers to access:** such as language and financial barriers.
* **Wider implications of disability:** consider the wider impact on families and caregivers, along with the mental health implications of disabilities.
* **Understand the need for stability:** this is in terms of their supports (and support workers), but also the desire of people with disability to be able to plan for the future. Additionally, understand that some disabilities are progressive and will require additional supports.

### Other comments

**Question:** Do you have any other comments about the NDIS Reform Bill or how PWDA should respond to the NDIS Review's recommendations?

Note: the responses to this question were extensive and detailed.

The key themes to emerge from this final question were:

* **A strong desire for consultation engagement and co-design:** people with disability should be consulted, and engaged in designing the policies and processes that will impact on them.
* **The need for individualised support and plans:** members stressed the need for people with disability to be treated as individuals, and for the supports and plans afforded to them to be designed around their unique needs, goals and circumstances. Members again highlighted the need to consider that their capabilities (and therefore needs) can fluctuate and/or may worsen over time.
* **Protecting choice and control:** members consider this to be a central pillar of the NDIS, and something that needs to be protected. Selecting the supports and providers that best suit them is critical.
* **People are using ‘workarounds’**: due to lack of suitable services, members are using providers who are not NDIS registered, and who likely will be excluded from future funding (an example was purchasing incontinence pads from Coles as that is what is available and affordable).

# Summary of findings – Member consultations

### Consultation 1

### NDIA visibility over NDIS providers

**Question:** Our survey results indicate a majority of PWDA members DO support the National Disability Insurance Agency (NDIA) having visibility of all NDIS providers and workers. What are some ways to give the NDIA this visibility? (n=11)

* Some members suggested that the data that the NDIA requires for visibility already exists in the form of ABNs, invoices and registrations, and that it should be mandatory for these to be supplied to the NDIA.
* Others suggested that more transparency for participants was more vital, such as a service to rate and review providers or support workers.

### Missing Supports

**Question:** Are there types of supports that you think the Bill has missed? (n=14)

* In terms of specific supports, advocacy supports were identified as a gap in the Bill by several members.
* Some members raised concerns about the supports people with disability may need to live a full life such as transport, holidays and supports for arts and cultural participation.
* Members however were clearly most concerned about the curtailing of their choice in what supports best suited them.
* As one participant said *“We shouldn’t be told what we need. I know what I need. I know what works for me.”*
* Some thought the Bill was lacking in key information, which prompted concern about what would exactly be covered.
* Though not directly covered by this question, members also raised concerns about the Bill (in general) lacking protections for people with a disability (against abuse or neglect).

### **Changes to Housing and Living Supports**

**Question:** Do you support these proposed changes to Housing and Living Supports? (n=12)

* **100% of members disagree with the proposed changes to Housing and Living Supports.**
* Members were vehemently opposed to this change. This change undermined the choice and control that is a central pillar to the NDIS. This approach is seen as a one size fits all and a change designed in the interests of capping funding for the NDIS, not in providing adequate care to people with disability.
* In addition to some people with disability simply requiring more support than others, members were highly concerned about the lack of choice over who they or people with disability in live with.
* To some, this was a violation of the human rights of people with disability.

*“It takes away need from people with disability in order to fulfil a need of the NDIS (funding)” “*

*A blanket approach cannot provide for individual needs! Choice and control must be upheld!” “These recommendations contradict the NDIS principles of CHOICE & CONTROL!!”*

### Final Thoughts

**Question:** What else would you like to share? (n=10)

The final comments of member reflected two themes:

* **Disability representation:** that the ‘system’, including the NDIS, the NDIA, service providers, peak bodies and those leading the review should be staffed by people with disability and have people with disability as their focus.
* **Rejection of the Bill:** members want PWDA to reject and campaign against the Bill on their behalf.

### Consultation 2

### Use of providers and support workers

**Question:** How do you use providers and workers to achieve everyday things and goals? How do you use your plans creatively that’s getting you a good outcome? (n=18)

* For many in this consultation, NDIS providers and workers are delivering supports that are essential to their existence.
* For these members, support workers provide food, the ability to leave the house and get to medical appointments.
* For others their support workers or providers facilitate greater independence and/or undertake personal care that they find difficult.
* Some commented that they purposefully don’t use registered providers to allow them to have greater flexibility and autonomy over how their supports are delivered. Negotiating with non-registered providers and thinking laterally has also – in the opinion of the members consulted – resulted in cheaper, and more useful services (such as the installation of a tabletop dishwasher).
* Members acknowledged that without the flexibility to employ non-registered support workers many of the supports they currently receive would not be available to them.

*“By being an extension of me so that when my disability gets in the way it doesn’t stop me I can keep going”*

*“To be able to prepare and cook meals, so I can eat. To be able to attend therapy and medical and other appointments. I'd literally die without NDIS supports. My teen who is also disabled and in my full- time care would end up in state "care".”*

### Needs based assessment

**Question:** Do you support the proposal to move to a model of needs-based assessments to determine access to the NDIS? (n=25)

* **Almost half (12/25, 48%) disagree with this change.**
* Members commonly disagreed with the change to needs-based funding due to a belief that no ‘tool’ would be able to accurately assess the needs of all people with disability.
* For some there was a belief that their disability was too complex, or their needs were to prone to fluctuations to be accurately assessed by anyone other than a treating therapist or allied health professionals.
* There is concern that the assessment will be undertaking by unqualified workers, who potentially have an interest in ensuring people cannot access the scheme (i.e. if the assessments are not independent).
* For some, this is an attempt at reintroducing ‘independent assessments’.
* **Almost one-quarter (6/25, 24%) partly agree**
* These members partly agree as they agree with ‘the premise’ but question the execution, particularly the lack of detail around what this will mean in practice. As with the above, members question how a tool could accurately measure their needs and question the independence of the assessors.
* **Just three agree (3/25, 12%)**
* **The remainder (4/24, 16%) were unsure** – primarily due to a lack of information.

“Hire allied health professionals to avoid putting participants through the trauma of assessments using

what tool? no one tool will accommodate all disabilities”

“Current therapist who’ve knows us sometimes decades understand needs much better. Especially fluctuating needs.”

“Determining peoples budgets through needs-based assessments is dangerous and will result in reduced support for people with episodic and variable disabilities - it will be about how you 'perform' on the day.”

### Use of funds

**Question:** Are there any supports you currently rely on that you are worried could be considered one or more of those things? If you had to replace the supports you’re worried might not be covered by these categories where else could you get the support from? And what impact could that have on you or your plan? (n=16)

* 79% of **members said that they were worried that one or more of the supports they rely on could fall into a category that NDIS funding could not be spent on** (as outlined by the Bill).
* Most common amongst these were concerns about household appliances (such as dishwashers) and holidays (more often referred to as respite by the members).
* Most felt that if the services they used and needed were no longer covered by the proposed categories, there would be no ‘alternatives’ or options to replace them.

“There are no alternatives. The white list and black list are just plain dangerous.”

“There is no other way to do these things so my personal and work opportunities will be taken away”

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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