

People with Disabilities WA  
individual & systemic advocacy



**Submission**

**NDIS Act Review and Participant Service Guarantee (Tune Review)**

Department of Social Services

People with Disabilities (WA) Inc. (PWdWA) would like to thank the Australian Government – Department of Social Services (DSS) for the opportunity to provide comment for their review into the operation of the *National Disability Insurance Scheme Act 2013* (NDIS Act).

PWdWA is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with disabilities via individual and systemic advocacy.

PWdWA is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

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### **People with disabilities WA (PWdWA)**

Since 1981 PWdWA has been the peak disability consumer organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, neurological, psychosocial, or sensory disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disabilities and aims to empower the voices of all people with disabilities in Western Australia.

### **Introduction**

PWdWA welcomes the opportunity to provide comment to DSS on the operation of the NDIS Act and the new proposed NDIS Participant Service Guarantee. People With disabilities WA receives both state and federal funding to provide advocacy around issues experienced by the community concerning the National Disability Insurance Scheme (NDIS). In particular we are funded by the Department of Social Services to provide support with NDIS Appeals.

People's fair access to supports under the NDIS is an extremely important aspect of PWdWA's advocacy work at both a systemic and individual level. As the peak consumer voice for people with disability in Western Australia (WA), our submission is compiled on the experiences of people with disability, their families and carers. We have provided case studies where appropriate to furnish our statements.

PWdWA is extremely concerned with the rising number of issues being considered by our advocates in relation to NDIS. The points raised in this submission are reflective of the hundreds of people we have assisted in advocacy on NDIS over the past year (300 in 2018-19). Quotes and graphs are taken from our survey, which to date has over 345 respondents, and the focus groups we have attended and facilitated.

This submission provides a number of recommendations that PWdWA strongly urges DSS to consider. These recommendations have been developed as a result of issues brought to our attention through our individual advocacy work and systemic NDIS work, including our NDIS Experience Survey. Consumers of Mental Health WA (COMHWA) have specifically provided input and recommendations to our responses to the Participant Service Guarantee. Our responses are also informed through PWDWA collaboration with Advocacy WA, Ethnic Disability Advocacy Centre, Explorability, Sussex Street Community Legal Service, Midlas and Your Say. Advocacy organisations are extremely concerned that the number and complexity of cases relating to NDIS is increasing, in part due to issue with the current legislation, and we are unable to currently meet the demand for advocacy on NDIS issues.

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The structure of this submission is:

Section 1: Summary of Recommendations

Section 2: Highlighted issues

This section summarises the various issues brought to our attention through our individual advocacy work and systemic NDIS work, including our NDIS Experience Survey. It has a number of recommendations relating to legislative change that is needed.

Section 3: Feedback on proposed Participant Service Guarantee

This section provides feedback on what should be included in the new NDIS Participant Service Guarantee based on the feedback we have received from our members, the community and the experiences of the people we support.

## Section 1 – Summary of Recommendations

### Improving decision making clarity, information and justification

#### Recommendation 1

That the legislation is amended in Division 2, 34(e) to be about what is reasonable for that person in their situation. The emphasis on what is reasonable for the general community ignores the socio-economic reality of many people with disability, their families and carers.

#### Recommendation 2

That any decision to reject or refuse a person access to the scheme, or refuse requested funded supports through the planning process is provided both verbally (or through interpreters or other relevant means) and in writing, and include provision of justification from the planner related to the person's individual application or individual goals, objectives and aspirations. This should include amending of Section 2(7) to include the term 'decisions' for clarity.

#### Recommendation 3

Amend the legislation to:

- **Require** the NDIA CEO to request any reports or assessments that the agency needs to make a fully informed decision.
- Clarify the **minimum** level of reporting required and allow for reports from non-medical practitioners for supplementary reports.
- Clearly state the **circumstances** under which the CEO will **fund reports or assessments** including where the participant or potential participant does not have the financial means and the requested report or assessment cannot be otherwise funded.

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### Improving timeframes and timeliness for participants

#### Recommendation 4

Amend Section 32(3) of the legislation to provide a specified timeframe for a plan to be approved after a person is found eligible for the scheme. We believe a timeframe of no longer than 3 months between access being met and a plan being provided would be reasonable.

#### Recommendation 5

Amend Section 48(3) of the legislation to provide a specified timeframe for a plan to be approved after a review is completed. We believe a timeframe of no longer than 30 business days would be reasonable. Amend Section 39 to include that the plan is provided in a format accessible to the person.

#### Recommendation 6

Amend Section 100(6) of the legislation to provide a specified timeframe for an s100 to be completed. We believe a timeframe of no longer than 3 months between submitting the s100 request and a decision being made is reasonable.

#### Recommendation 7

Amend Section 48(3) in the legislation to provide a specified timeframe for responding to a Change of Circumstances/s48. We believe a timeframe of no longer than 1 month between submitting the Change of Circumstances/s48 review request and a new or amended plan being issued is reasonable.

### Improving processes on urgent situations and plan amendments

#### Recommendations 8

The legislation should be updated to include a definition of urgent as it relates to specified matters and a specified timeframe of 2 weeks for responding to matters, which meet the urgent criteria. The urgent criteria should apply to the following matters at a minimum:

- Decisions about Internal Reviews
- Completing plans resulting from Access Met decisions
- Completing plans resulting from Change of Circumstances/s48 Review Requests and Plan Amendments, which the agency agrees to conduct.

We believe matters should meet urgent criteria if the following circumstances apply:

- risk of harm to the health or well-being of a person;
- instability in the accommodation arrangements of a person, including the risk of homelessness;
- instability in the care arrangements of a person, including the risk of a primary carer not being able to provide care; and
- risk associated with the nature of the person's disability, including the risk of rapid deterioration or progression.

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### Recommendation 9

A new section relating to plan amendments be included in the legislation. This section should allow for plan amendments without the requirement for a review, or creation a new plan under the following circumstances:

- Where there was a planning error including but not limited to:
  - Supports being miscategorised
  - Supports deemed reasonable and necessary discussed in planning meeting but not included in plan
- Changes to the way plan funds are managed
- Changes to goals which do not result in a change to funded supports
- Changes in funded supports where the change would result in increased funding of 10% or less than the total funded supports in the plan including but not limited to:
  - Reasonable and necessary supports not discussed in planning meeting but where participant is found to be eligible later but within the plan's timeframe
  - Where products are essential to being able to live a good life (e.g. incontinence products) there is good evidence and can provide receipts for the products
- Changes in personal details (including legal name changes)
- Where participant has been unable to get their plan started (not working) after 3 months – minimum support coordination so as to get plan going
- Unforeseen circumstances which create a temporary need for additional funding including but not limited to
  - Natural Disaster
  - Temporary carer absence
  - Episodic event
  - Accident or Injury

### Provide for a draft plan

### Recommendation 10

Amend the legislation to require the agency to provide a draft plan to a participant within 5 business days.

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### Improve plan review and end processes

#### Recommendation 11

Amend the legislation to require any significant increase or decreases in funded supports in plans over \$50,000 to be reviewed by the CEO, or their delegate. For the purpose of this amendment, we believe a change of 25% or more of the total funded supports of plans over \$50,000 should be considered significant.

#### Recommendation 12

Amend the legislation to specify plans can be 'rolled' over rather than requiring an end of plan review where if it is demonstrated that the supports in the plan meet the needs of the participant and the goals in the plan are being achieved.

#### Recommendation 13

The legislation should be amended so that the s100 Internal Review that is triggered applies to the supports that are included in the persons plan, not the decision whether or not to conduct a plan review.

#### Recommendation 14

Amend the legislation to ensure it clearly states that an s100 Internal Review can remain in effect where a plan review or amendment is being offered.

### Ensure rights to advocacy are upheld

#### Recommendation 15

Section 5 and 100(2) of the legislation be amended to reference a person right to have an advocate act on their behalf and include a definition of independent advocacy.

### Improve access process

#### Recommendation 16

Amend the legislation to increase the timeframe for submitting additional information or reports to 3 months before the access request is taken to be withdrawn.

### Improve rights of people with disability regarding nominees and guardianship

#### Recommendation 17

Amend the legislation in relation to nominees:

- remove the power of the nominee to act or not act based on their opinion of whether doing or not doing an act promotes the person and social wellbeing of the participant.
- require a nominee to carry out the views of the participant unless it is independently determined the participant is unable to make decisions even with supported decision making.

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- require a nominee to undertake supported decision making where required, and have regard to the views of the participant
- require nominees to declare a conflict of interest and where it exists provide at minimum yearly reports as to how any conflict of interest has been managed.
- require the appointment of nominees to be reviewed no less than every 3 years.
- require NDIA to include appropriate funded supports in plan to help minimise and eliminate the need for a nominee where conflict of interest exists e.g. fund supported decision making

### Recommendation 18

Amend the legislation to provide a clear definition of a legal guardian and recognise the authority of legal guardians to act on participants behalf. Ensure the legislation is clear that Guardians are not required if a person is unable to act or make their own decision.

### Recommendation 19

Amend the legislation in the nominee section to refer back to Section 17A (3) (b) recognising capacity. Refer to principles of supported decision making in the legislation and rules to support capacity. Refer to relevant state legislation in each jurisdiction on capacity.

### Improve language of Reviews

### Recommendation 20

Amend the legislation to call an s100 Review of a Reviewable Decision (AKA Internal Review) an Internal Appeal and clearly differentiate this process from a plan review.

### Recommendation 21

Amend Section 48 of the legislation to define two types of plan reviews:

- Scheduled Plan Review – a review which occurs within 6 weeks of the end date of a plan and is initiated by NDIA
- Unscheduled Plan Review – a review which can occur anytime within the lifetime of a plan at the request of a participant or the CEO

### A representative Board to set organisational culture

### Recommendation 22

That the section of legislation relating to Board Members be amended to mandate 50% of the Board to be people with disability.

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### Participant Guarantee: Timely

#### Recommendation 23

A new principle in the Participant Service Guarantee should be included:

‘Easy to Navigate: The NDIS process is easy to understand and use.’

#### Recommendation 24

The ‘Timely’ principle needs to include guarantees for participants around timeliness in accessing information and responses outside of specific legislated actions such as:

- Access to timely and accurate information from NDIA front of house and call centre staff
- Timely action on day-to-day processes such as uploading documents
- Processes and procedures which support the implementation of legislated timeframes and quick responses

#### Recommendation 25

The Agency adopt an Application Progress Notification System to allow applicants to track progress, similar to online deliveries.

#### Recommendation 26

Adequate numbers of LAC partners to be in place, and funding of Support Coordination must be made available to participants to assist with the understanding and implementation of their plans.

#### Recommendation 27

As part of the participant guarantee simple decision support tools to assist participants with processes such as access, planning, plan implementation and reviews are provided and made available throughout all points of the NDIS journey.

### Participant Guarantee: Engaged

#### Recommendation 28

The ‘Engaged’ principle needs to include a commitment to true co-design, with diverse representation in co-design groups.

#### Recommendation 29

Transparency of the people involved and process and /or problems being worked on must be included in the ‘Engaged’ principle.

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### Participant Guarantee: Expert

#### Recommendation 30

Include in the principle on 'Expert' that people with disability, and their families and carers as appropriate, have expertise in their own disability, functionality, and situation. Include that planners will listen.

#### Recommendation 31

NDIA and LAC partner organisations recruit more people with disability into planning roles, and staff receive regular training **from** people with disability with expertise.

#### Recommendation 32

Utilise peer champions to work alongside LAC Partners to get the message across in a consistent manner and support people to engage with and participate in NDIS application, planning, plan implementation and review processes.

### Participant Guarantee: Connected

#### Recommendation 33

The 'Connected' principle in the Participant Guarantee needs to include that the NDIA educate other agencies and services of its role, and provide pathways to community and mainstream services. The NDIA staff and LAC partners must be knowledgeable of complimentary services and encourage their use as well as alternative services.

#### Recommendation 34

In particular 'Connected' must include greater awareness and education targeted to health professionals to improve quality of evidence provided to potential participants.

### Participant Guarantee: Valued

#### Recommendation 35

The 'Valued' principle must be supported by good information and advocacy provision that is adequately funded so people know where to go for support.

### Participant Guarantee: Decisions

#### Recommendation 36

Remove the term 'on merit' from the principle and replace with 'on principles of equity'.

### Participant Guarantee: Accessible

#### Recommendation 37

This 'Accessible' principle should be split to clarify 1. An accessible scheme for all people with disability; and 2. A culturally appropriate scheme that caters for First Nations people, CALD, LGBTIQI+ in information and engagement.

### Recommendation 38

To be accessible to harder to reach people the agency have outreach / mobile models of engagement to assist potentially eligible participants apply for NDIS to circumvent lack of access to appropriate IT facilities eg; people who are homeless, in hostels, or hospitals. That this is followed through with planning.

### Conclusion/ Review

### Recommendation 39

That the NDIA undergo 3 yearly external evaluation/ Audit by people with disability against the NDIS principles and objects in the NDIS Act.

## Section 2 – Highlighted Issues

In the 2018-19 Financial Year, NDIS represented one third of all issues dealt with by PwDWA. While this encompassed a number of different types of issues related to NDIS there were common themes amongst cases. Themes included the length of time for NDIS to respond to a range of matters, issues with the handling of s100 Internal Reviews, issues with accessing information that would assist people to best navigate NDIS systems and matters relating to consent and conflict of interest.

### Adequate explanations of decisions

The NDIS Act states there is a requirement to provide an explanation of information to the maximum extent possible to the person e.g. Section 7. It states that it applies to notice, approved forms or information under the NDIS Act. It is not clear enough whether this applies to *reviewable decisions* made under the NDIS Act e.g. decision not to grant access, decision to approve the statement of participant supports etc.

Our experience has been that the information provided to people who do not meet the access criteria is overly formal, quotes the legislation and operational guidelines and does not provide information specific to the person's evidence or circumstances. It is also overly full of jargon and not written in plain English. People who come to our advocacy service often do not understand the letter they have received and are at a loss on what to do next. Without an advocate to review their evidence and provide recommendations on the types of assessments or reports needed many of the people we support would not have the evidence required by NDIA to prove their eligibility.

The provision of a quality explanation, which helps the person understand the decision to the maximum extent possible, would assist persons with either reviewing the decision under s100 or making a new access request.

Additionally decisions made about what supports to include in a participants plan are not explained to the maximum extent possible as part of the planning process. Many of the people we support indicate that the conversations they have in planning meetings and supports discussed are vastly different to the plan received. The

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process becomes about the planner fitting the participant to reasonable and necessary criteria rather than the outcomes identified by the participant and the choice and control to reach them.

The response from the PWdWA survey and peer support group interactions clearly demonstrates that people do not know or understand why decisions about their plan are made. Participants have shared that they have gone into the planning meeting well prepared and have spent hours preparing for the meeting. They produce all the relevant reports to support their plan only to find that their requests are denied. When asked for an explanation they are advised it's not reasonable and necessary or provided with another vague response.

Participants are confused and left feeling let down and unsupported with a choice to accept the decision or muster the energy to fight it!

"I was more than ready for the Plan Review and was denied 89% of everything the specialists requested my son have. No valid reasons were provided for the reason of denial. Took 12 months for internal review to be done. Took 12 more months after that and still doing an external review. Accountants and Lawyers are saying things like 'Soft Tissue OT is just a massage' when I have provided Physio, OT and Psych reasons for requiring ST OT use. Assistive Technology has taken over a year to be looked at. Not approved, not finalised but looked at. There are things that we are entitled to but not offered or asked about because they feel we have too much already. Did I mention that we have waited over two years? My son was 5 when the review started. Now he's about to turn 7, he is 2 years behind in therapies and aid, he's no longer under 'Early Intervention'"

Your NDIS Experience 2019

Participants need a more formal process that explains why decisions have been made and relate this to their disability. All requests in the plan that are not supported should elicit a written and verbal explanation to the participants so that they have an understanding as to why supports have been denied. This will ensure a transparent process and not just a decision made by the interpretation of the planner on the day.

It would also assist people to understand what further evidence is required; especially where they go on to seek an s100. It could greatly improve the quality of evidence provided for the s100, which in turn will ensure that issues with supports are resolved sooner, rather than being escalated to the AAT.

**Recommendation 1:** That the legislation is amended in Division 2, 34(e) to be about what is reasonable for **that person in their situation**. The emphasis on what is reasonable for the general community ignores the socio-economic reality of many people with disability, their families and carers.

**Recommendation 2:** That any decision to reject or refuse a person access to the scheme, or refuse requested funded supports through the planning process is provided both verbally (or through interpreters or other relevant means) and in

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writing, and include provision of justification from the planner related to the person's individual application or individual goals, objectives and aspirations. This should include amending of Section 2(7) to include the term 'decisions' for clarity.

### Failure to request further evidence or fund requests

There are a number of areas of the legislation where the CEO *may* make a request for further information, including undergoing assessment and requesting further reports e.g. Section 26, 36 and 50. The legislation also states that the NDIA *may* provide support (financial or otherwise) to participants or prospective participants in relation to doing things or meeting obligations under the NDIS Act (Section 6).

Although people are told verbally by the NDIA they need additional evidence to prove their eligibility or show that supports are reasonable and necessary, we have not seen one formal or written request for specific reports or assessments outside of AAT proceedings. Without a formal request for the required additional documentation, there is no opportunity to request the NDIA fund the assessment or report. Many of the people we support do not have the financial means to access the kind of evidence that would be required. They are precluded from accessing the scheme on financial grounds, meaning those most disadvantaged are facing further barriers. Additionally, by having a clear indication of what assessments or reports are required the person's ability to provide the evidence required to satisfy the NDIA is greatly improved.

A man with an Intellectual Disability sought advocacy support with a second Access Request. It was clear from the man's circumstances that he needed daily support but had never accessed disability services previously. After seeking additional evidence at his own cost, he was told verbally by NDIA that the report required the practitioner formally state he had an intellectual disability and he did not meet the access requirements. The advocate approached the organisation who had completed the assessment and requested that they amend the report so it satisfied NDIA's requirements. They refused because further testing was required to make a formal diagnosis. While the advocate was able to negotiate a reduction in the cost of the assessment the man still could not afford the assessment and decided that he was too tired to fight NDIA further.

For people seeking access to the NDIS, funding should be provided to assist with assessments, such as Occupational Therapy Functional Capacity Assessments, which would assist with demonstrating eligibility. For those whose issue is with funded supports, providing the opportunity to undertake the assessment or present the report before the NDIA makes a decision about the statement of supports will help reduce the number of requests under s100. Where it is anticipated that funding would be needed, or the provision of an assessment or report would take too long, supports should be specified in plans to enable assessment and reports to be produced.

We are concerned that the constant requesting of reports and assessments is indicative of a culture in the agency of a medical model of disability where the burden

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of proof is with the individual. Multiple forms of proof from Allied Health practitioners and medical professionals are considered necessary by the NDIA. For those that have disengaged from systems, may be homeless, or only have a GP it is reports from friends, family, and other community services workers that would be most useful and less costly

**Recommendation 3:** Amend the legislation to:

- **Require** the NDIA CEO to request any reports or assessments that the agency needs to make a fully informed decision.
- Clarify the **minimum** level of reporting required and allow for reports from non-medical practitioners for supplementary reports.
- Clearly state the **circumstances** under which the CEO will **fund reports or assessments** including where the participant or potential participant does not have the financial means and the requested report or assessment cannot be otherwise funded.

### Lack of specified timeframes

An ongoing trend in NDIS matters brought to advocacy organisations includes the lack of a timely response by NDIA. In some cases this is placing participants at significant risk. The impact on the mental wellbeing of participants and their families due to delays is also significant, with some people reporting suicidal ideation because of the long, ongoing battles with NDIA for access and reasonable and necessary supports.

Advocacy organisations and the community have experienced issues in the timeliness of responses by NDIA relating to the following areas:

- Uploading of information and response to email enquiries
- Providing a planning meeting after being found eligible
- Providing NDIS plan after planning meeting
- Responding to and actioning Internal Reviews
- Responding to and actioning Change of Circumstances
- Responding to and actioning complaints with 21 days
- Responding to and actioning issues flagged as urgent where there is real and imminent risk to the participant

Additionally the information provided by 'Your NDIS Experience' survey participants shows clear dissatisfaction with the wait times and delays for reviews, AT applications, receiving plans and responses to complaints.

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“I had to go through a very rigorous and expensive process to get my Application finalised and handed in to be told there could be a 6-9 month wait before I even hear if I am eligible!!”

“...still waiting for any response from NDIA after almost 4 months.”

“It took nearly 8 weeks for the Plan to come after the Planning meeting, The Planner did correspond via email and queried some things over phone,”

Your NDIS Experiences Survey 2019

### Providing a planning meeting after being found eligible

Both the community and advocacy agencies report lengthy delays of up to 4 months for planning meetings to occur after a person has been found eligible. In at least two instances, people have waited more than 12 months for planning meetings. People are also stuck waiting in hospital for plans to be developed, which is affecting the health system and the availability of beds. CoMHWA also report that anxiety and long waits with planning often results in disengagement from the system.

The legislation states that planning meetings should take places ‘as soon as reasonably practicable’. Our experience shows that this is not guaranteeing a participant timely access to planning and the commencement of their plans.

**Recommendation 4:** Amend Section 32(3) of the legislation to provide a specified timeframe for a plan to be approved after a person is found eligible for the scheme. We believe a timeframe of no longer than 3 months between access being met and a plan being provided would be reasonable.

### Providing NDIS plan after Planning Meeting

‘Your NDIS Experience’ participants as well as advocacy agencies across the state have stated that delays between planning meetings taking place and plans being received can be very long. Some of the survey participants indicated a period of 2-4 month delays from planning meetings to receiving a plan. Additionally PWdWA has experienced plans being provided months after being created effectively leaving little, if no, time for an s100 Internal Review to be lodged.

There is a guaranteed timeframe of 7 days between a plan coming into effect and a copy of the plan being provided to a participant. However there is no guaranteed timeframe between when a planning meeting takes place and a new plan is approved. Additionally, the NDIA provides the plan through the participant portal which is not always accessible. The practice of meeting with a Local Area Coordinator, and then sending the plan to an NDIA delegate for approval is also likely contributing to delays. NDIA need to streamline this process, however a guaranteed legislative timeframe will ensure participants receive the plan in a timely manner, and feel confident in their right to make a complaint if the timeframe is not met.

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**Recommendation 5:** Amend Section 48(3) of the legislation to provide a specified timeframe for a plan to be approved after a review is completed. We believe a timeframe of no longer than 30 business days would be reasonable. Amend Section 39 to include that the plan is provided in a format accessible to the person.

### Time taken for Decisions of s100 Internal Reviews

The May 2018 Report by the Commonwealth Ombudsman highlighted the issues with lengthy delays with s100 Internal Reviews (Internal Reviews). The report noted that at the time one third of all complaints it received about the scheme were to do with the lack of timely handling of Internal Reviews. The NDIA in their response committed to:

- Develop and implement process for contacting participants who have a pending request in the national backlog and inform them of the process moving forward
- Develop streamlined process for correcting simple plan errors
- A dedicated NDIA team being established to manage the backlog of reviews, including a process for resourcing

Currently there is still a long wait for Internal Reviews to be processed. The community and Advocacy organisations across WA have experienced NDIA still taking up to 7 months to provide a decision on Internal Reviews. Participants of the 'Your NDIS Experience' survey specifically indicated wait times of 3-9 months for Internal Reviews to be actioned.

Where an Internal Review is submitted close to the 3-month deadline this means the person is left under-supported for almost the entirety of their plan. In some cases annual reviews have occurred before the Internal Reviews has been considered.

Participants often resort to submitting complaints to have their Internal Review actioned. The current trend of response from NDIA to offer an s48 Review of the participants plan in exchange for withdrawal of the Internal Review is highly problematic and discussed in further detail below.

Due to the extremely long delays in actioning Internal Reviews and the growing demand for advocacy support many of the WA advocacy organisations are also forced to close cases without a resolution being known, so that people on waitlists can be assisted.

The legislation states a delegate must make a decision about an Internal Review 'as soon as reasonably practicable'. Our experience and feedback from the community shows that this is not guaranteeing participants a timely decision. It is resulting in stress, anxiety, frustration and a loss of faith in the system. It is also denying a person timely access to the supports they need and are entitled to.

A parent who submitted an Internal Review on behalf of their daughter called the NDIS Contact Centre 4 months after it had been submitted, asking for the Internal Review to be priority escalated. The call centre staff indicated they would action this. She called again a week later after receiving no response and was told the priority

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escalation had not been actioned and that the call centre staff would action it. Two weeks later she called again, only to be told that it had not been priority escalated and the person on the phone would complete that action. An advocate had to escalate the matter through internal pathways. It has been 5.5 months since the Internal Review was submitted and the NDIA has still not actioned it.

**Recommendation 6:** Amend Section 100(6) of the legislation to provide a specified timeframe for an s100 to be completed. We believe a timeframe of no longer than 3 months between submitting the s100 request and a decision being made is reasonable.

### Responding to and actioning Change of Circumstances

Advocacy organisations have received a number of complaints about Change of Circumstances/ s48 Review requests not being actioned by NDIA. We believe this is in part due to requests not being properly recorded by NDIA staff but also the lack of specified timeframe for completing the s48 Review.

In many circumstances the request involves a significant change to the availability of informal supports in a participants life and if not actioned quickly will place the person at risk. In some cases it has taken months for any acknowledgement or action to take place – often only after multiple complaints or escalation by advocacy agencies through specific crisis escalation points. The impact of not responding in a timely manner to change of circumstances is being felt by the hospital and health systems.

Section 48(3) of the NDIS Act states where the CEO agrees to conduct a review it must be completed 'as soon as reasonably practicable'. Our experience and feedback from the community shows that this is not guaranteeing participants timely access to a new or amended plan, which meets their needs. It is resulting in stress, anxiety, frustration and a loss of faith in the system. It is also denying a person timely access to the supports they need and are entitled to.

A primary carer had advised NDIA, through a Change of Circumstances/s48 request, that they would not be able to care for their spouse (who required 24 hour care) due to upcoming surgery. The carer provided NDIA with 3 months' notice, requesting that the participants plan have an unscheduled review to ensure reasonable and necessary supports were available. Two weeks before the surgery NDIA had still not responded to the Change of Circumstances/s48 request. The carer was concerned that his spouse would be at real risk of harm if adequate supports were not implemented. With the support of an advocate escalating the matter through a specific escalation pathway the Change of Circumstances was finally actioned, but not before the delay had caused significant distress to the carer.

A mother of a child with a disability shared her experience as part of the systemic work PwDWA are undertaking. She requested a review of her daughters plan based upon changed circumstances within her family unit. She herself had been diagnosed with autism and mental health and she was nursing her elderly parent who was diagnosed with terminal cancer. Her teenage daughter who has autism, hearing loss,

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oppositional defiance disorder and intellectual disability required more support as her plan did not offer any support in the home and minimal social and civic participation. The s48 was lodged by the mother in June 2019 and she has still not had a response in October despite numerous calls to NDIS call centre who have reassured her it's on the system but there has a back log. This has caused enormous pressure and stress to the mother who is now medicated for depression and is unable to manage her employment in which she is the sole provider for the family. This has caused financial pressure and hardship to this family unit.

**Recommendation 7:** Amend Section 48(3) in the legislation to provide a specified timeframe for responding to a Change of Circumstances/s48. We believe a timeframe of no longer than 1 month between submitting the Change of Circumstances/s48 review request and a new or amended plan being issued is reasonable.

### Responding to and actioning issues flagged as urgent where there is real and imminent risk to the participant

Advocacy organisations are highly concerned with the length of time it takes for NDIA to respond and take action where there is imminent risk to the participant or their informal supports. PWdWA have support people on 6 recent occasions to flag Internal Reviews as priority where it still took over 1 month for the Internal Review to be actioned.

Participants and their families are flagging urgent and priority issues with NDIA at the time they have submitted documents like Internal Reviews or Change of Circumstances, by multiple contacts with the NDIS Contact Centre and through complaints. Even with all of these avenues being actioned the response is slow.

We are finding that we increasingly need to use advocacy specific escalation pathways to ensure urgent matters are being actioned. While this helps people who are accessing advocacy it leaves us concerned for those who are not and are in similar situations.

An advocate supported a participant to submit an Internal Review in early December. In late February the advocate requested on the participant's behalf that the Internal Review be priority escalated due to the risk of suicide, and the lack of psychological supports provided in the plan. There was no response from NDIA. It was escalated again with NDIS Contact Centre staff in mid-April and the call centre staff member advised they had flagged the issue as urgent and there would be response within 48 hours. It was finally escalated through advocacy specific escalation pathways a week later due to significant concerns for the participant's wellbeing and new plan was finally issued in mid-June.

In a recent meeting with a peer group of people from the deafblind community a lady shared that she has been waiting since April 2019 for an internal review of her plan due to services being omitted by the planner. She requested an update as to why her review had not been dealt with and the call centre advised that the review had been cancelled. She requested that the internal review be reinstated which it was;

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but she still has had no contact from NDIS regarding the review. This has meant that she has had to cancel pool therapy that is crucial to her mobility and wellbeing until she can get the plan reviewed and the supports included in her plan. This is now 6 months since she requested an internal review.

There is nothing in the legislation which identifies what matters may require urgent response, and what the criteria for an urgent matter would be. As such, there is also no specified timeframe for responding to urgent matters. This is resulting in long delays, and placing many participants at significant risk.

**Recommendations 8:** The legislation should be updated to include a definition of urgent as it relates to specified matters and a specified timeframe of 2 weeks for responding to matters, which meet the urgent criteria. The urgent criteria should apply to the following matters at a minimum:

- Decisions about Internal Reviews
- Completing plans resulting from Access Met decisions
- Completing plans resulting from Change of Circumstances/s48 Review Requests and Plan Amendments, which the agency agrees to conduct.

We believe matters should meet urgent criteria if the following circumstances apply:

- risk of harm to the health or well-being of a person;
- instability in the accommodation arrangements of a person, including the risk of homelessness;
- instability in the care arrangements of a person, including the risk of a primary carer not being able to provide care; and
- risk associated with the nature of the person's disability, including the risk of rapid deterioration or progression.

### No Ability to Amend Plans

There is a high level of frustration from participants where simple planning errors such as a mistake in the number of hours cannot go through a streamlined process to be corrected quickly and efficiently.

We have seen many people transfer from WA NDIS under the 'like-for-like' bilateral agreement erroneously provided with less supports than in their WA NDIS plan. We have also seen people where supports hours have been funding under the wrong specified support preventing them from accessing necessary supports such as therapies.

A participant was receiving a WANDIS plan with 2-1 support funding due to behavioural issues. This was reflected in the wording of the WANDIS plan and evidence but there was an error in the plan itself where the dollar amounts didn't reflect the 2-1 (but it was being provided and funded regardless). The NDIS planner failed to take this into account in transferring like-for-like as is required under the bilateral agreement in WA. Despite this being a clear case of planner error the family was required to submit an Internal Review. A review of the plan completed 9 months after the plan was approved. During this time, the participant and his family were at

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risk of harm, did not receive 2-1 supports and had to stretch limited funding as best they could. The participants behaviours escalated during this time due to the lack of funded supports.

Despite a 'light touch review' mechanism existing many people are being told by NDIA Contact Centre staff, LACs and NDIS planners to complete an s100 Internal Review, which is taking months.

One of the complications that we have seen in requiring a plan to be replaced is that providers can no longer access payments for services provided under the old plan, and self-managed participants have no ability to claim for invoices for expired plans. It is reasonably anticipated that all invoices should be rectified before the end of a plan's lifespan. However, where the plan is replaced before it ends there may be timing issues for invoices and payments. Our experience has been that providers seek a resolution with the participant rather than NDIA in these circumstances, threatening legal action and withdrawal of services.

Division 4 of the legislation does not allow for the amendment of a plan. Even with a change to participant goals (s47) which does not result in a change to funded supports, the plan must be replaced with a new plan. The only way for a plan to be 'varied' under the legislation is for it to undergo an Internal Review within the specified timeframe.

**Recommendation 9:** A new section relating to plan amendments be included in the legislation. This section should allow for plan amendments without the requirement for a review, or creation a new plan under the following circumstances:

- Where there was a planning error including but not limited to:
  - Supports being miscategorised
  - Supports deemed reasonable and necessary discussed in planning meeting but not included in plan
- Changes to the way plan funds are managed
- Changes to goals which do not result in a change to funded supports
- Changes in funded supports where the change would result in increased funding of 10% or less than the total funded supports in the plan including but not limited to:
  - Reasonable and necessary supports not discussed in planning meeting but where participant is found to be eligible later but within the plan's timeframe
  - Where products are essential to being able to live a good life (e.g. incontinence products) there is good evidence and can provide receipts for the products
- Changes in personal details (including legal name changes)
- Where participant has been unable to get their plan started (not working) after 3 months – minimum support coordination so as to get plan going
- Unforeseen circumstances which create a temporary need for additional funding including but not limited to
  - Natural Disaster

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- Temporary carer absence
- Episodic event
- Accident or Injury

### Ability to access a draft or preview plan

In regards to making draft plans available – this would eliminate many common issues the PWdWA are seeing with participant plans including:

- wrongly categorised supports,
- funding discussed in planning meetings which are accidentally left out of plan,
- issues with the way funding management has been allocated
- Issues with transitions from WANDIS to NDIS which is guaranteed to be like for like but which is often not occurring.

Individuals and families are reporting they are leaving planning meetings with the expectation that what was discussed in the meeting was captured by the planner and will transfer into the plan this is often not the case. This is a common theme that is being reported by people which results in an internal review process more often than not because the “light touch review “ is not offered. The other alarming message to people from planners is that if they are not happy with the feedback the planner is providing in the meeting the planners are saying “if you’re not happy when you receive the plan you can request an internal review” not explaining how long this process can take.

“The time between when a plan is approved and the way it is delivered to the participant is not acceptable. I think you should be able to read it as a document (as you would any other legal document) and have sufficient time to check it and ask for amendments if possible”

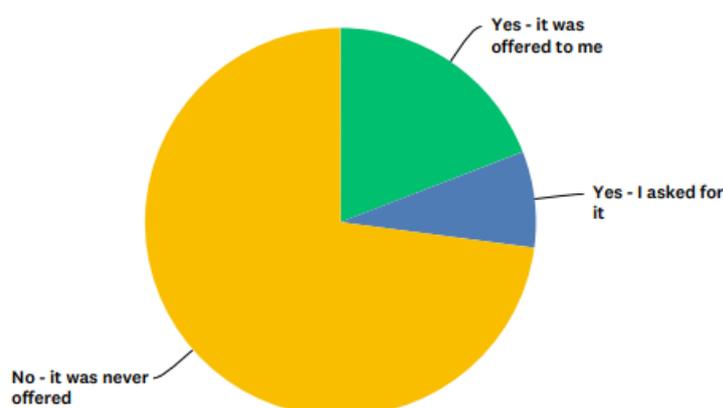
Your NDIS Experiences survey 2019

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### Your NDIS Experience

Q9 Were you given the opportunity to review your plan before it was finalised (a finalised plan is usually posted to you in paper format and put on the Participant portal)?

Answered: 225 Skipped: 87



| ANSWER CHOICES             | RESPONSES |     |
|----------------------------|-----------|-----|
| Yes - it was offered to me | 19.11%    | 43  |
| Yes - I asked for it       | 8.00%     | 18  |
| No - it was never offered  | 72.89%    | 164 |
| TOTAL                      |           | 225 |

While amending the legislation to allow for a plan amendment would ensure that mistakes do not require a new plan to be issued or Internal Review be required, it would be a more streamlined and fair process to allow for required changes to be made before a plan is finalised.

**Recommendation 10:** Amend the legislation to require the agency to provide a draft plan to a participant within 5 business days.

### Incidence, severity and impact of plan gaps

Over a 12 months period PWdWA assisted with 76 plan reviews relating to inadequate funding for reasonable and necessary supports. This included:

- lack of core support funding
- lack of therapy funding
- Assistive Technology not being approved or included in plans

Of those 76, 21 were related to significant gaps in funding. In some cases, the gap in funding amounts to up to \$100,000. In many cases, the gap in plans is placing the participant and their family at risk of harm. This includes where inadequate supports result in the participant being at risk of harming themselves, harming family and has

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restricted access to the community because it is unsafe without adequate supports. It also includes risks of family breakdowns and burnout of informal supports. Additionally, the fight to address gaps in plans can have a severe and longstanding impact on the mental health of the participants and their informal supports.

A family at a peer support group PWdWA recently attended shared an example of the impact on primary carers. The single mother has mental health and depression issues and her daughter has complex needs and behavioural issues. The lack of supports built into the daughter's plan resulted in her mother having a nervous breakdown and the elderly 80 yr. old grandmother having to step in and look after them both. There was nothing in the current plan to provide urgent support or back up because there were no supports in the plan. At the time of the initial planning meeting, the planner told the mother she was expecting too much from NDIS. The plan has been in the system to be reviewed and 7 months later the plan has yet to be reviewed and is coming up for a 12-month review.

PWdWA are only one agency, and we are aware the other advocacy agencies in WA have also had high numbers of NDIS reviews and appeals related to gaps in plan funding. We are also aware that many people submit reviews related to gaps in funding without the support of an advocate. Demand for assistance with NDIS plan matters has been so high that most advocacy agencies in WA now have a waitlist and PWdWA had to close its waitlist for on two occasions because it became so high.

“Shocking leaving a family and child without support and the extra stress involved in trying to get it back”

Your NDIS Experience survey 2019

**Recommendation 11:** Amend the legislation to require any significant increase or decreases in funded supports in plans over \$50,000 to be reviewed by the CEO, or their delegate. For the purpose of this amendment, we believe a change of 25% or more of the total funded supports of plans over \$50,000 should be considered significant.

### The circumstances in which plans could be automatically rolled-over

At the time of review of a plan if it is demonstrated that the supports in the plan meet the needs of the participant and the goals in the plan are being achieved the plan should be considered to be automatically rolled over. The plans are developmental and focused on building capacity however there has to be an acknowledgement that some participants will always require support in their plans to meet their needs. Participants having to continue to fight for reasonable and necessary supports every 12 months cause unnecessary stress, anxiety and pain to participants and their families.

There appears to be an assumption by planners, or direction by the agency, that plans should be reduced each year. Where there are clearly established needs for

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supports these should be rolled over unless there is a change of circumstances resulting in increased needs. Similarly, where there is a clearly establish need for consumables and AT repairs these should be rolled over unless the participant indicates needs have increased.

An example of this is a family with a daughter who has profound and significant physical disabilities reported that in the second plan they went to the planner with everything documented about their daughters supports. This included all equipment, consumables, personal care, community and civic participation and demonstrated conclusively the last 12-month plan had been successful in meeting their daughter's needs no increase required. The planner commended them on how well prepared they were and said they had made her job easy. The plan came back rewritten with half the supports missing requiring an internal review.

'Not enough funding in the plan initially. Each plan is looked at what \$\$\$ can be reduced. System does not consider issues like MS where there is multiple disabilities "

Your NDIS Experience survey 2019

**Recommendation 12:** Amend the legislation to specify plans can be 'rolled' over rather than requiring an end of plan review where if it is demonstrated that the supports in the plan meet the needs of the participant and the goals in the plan are being achieved.

### Decision not to conduct an s48 review

The legislation currently states that after an s48 review request has been submitted the CEO has 14 days to decide if they will conduct the review. If, after 14 days no decision they legislation states that this is considered a decision not to conduct the s48 review. It then states that this automatically triggers an Internal Review.

Currently the Internal Review that is triggered applies specifically to the decision not to conduct an s48 review. The outcome of this is that people can wait an inordinately long time for an Internal Review decision, which only relates to whether or not an unscheduled plan review must take place. It does not actually resolve the issue with the funded supports, which is the reason why an s48 review request was made.

PWdWA have support two people who have experienced this issue in the last 6 months. In both cases, the time taken to follow through the convoluted process to get an actual decision about funded supports was excessive and required the matters to be escalated to the AAT for a review of the supports in the plan to be triggered.

**Recommendation 13:** The legislation should be amended so that the s100 Internal Review that is triggered applies to the supports that are included in the persons plan, not the decision whether or not to conduct a plan review.

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### NDIA requesting withdrawals of s100 Internal Reviews in favour of s48 Unscheduled Reviews

Across WA we are seeing a trend of NDIA offering s48 reviews where people have requested Internal Reviews. In many cases, this is coming after lengthy delays to having the Internal Review actioned, and where families are very vulnerable, in desperate situations and at imminent risk of harm.

The s48 review is being sold as a 'faster' option to resolve the issue with funded supports. What is happening is that in choosing to have the s48 review, the s100 is then being withdrawn and removing people's right to appeal. This has also been experienced by people accessing individual advocacy supports through other Western Australian advocacy organisations including Midlas, Sussex Street Community Law Service IDAS, Explorability, and Your Say - Uniting Care West.

NDIA are not adequately explaining that in agreeing to the s48 review the person is also agreeing to withdraw the Internal Review and what that means for their right to appeal. Many of the people we support have been under the impression that the planning meeting they have agreed to is as a result of the Internal Review and if they are not happy with the outcome they will be able to appeal at the AAT. We have seen situations where the planners who have been allocated to the s48 have no idea that an Internal Review was ever lodged and have not accessed, or reviewed the information provided as part of the s100. We have had at least two advocacy cases now where the participant is not receiving the supports they need as a result of the s48 and has had to submit a second Internal Review instead of being able to escalate their appeal to the AAT. In both cases the participants, and their family, are incredibly vulnerable and this has further added to their stress and anxiety. This is not procedurally fair, denies natural justice and is a process that further disempowers people.

After transferring from WANDIS a mother requested an Internal Review of her daughters plan in February 2019. This was requested as a priority Internal Review due to risk of harm to the participant and to others around them, and related to the need for the participant to have 24 hour supports in place to remain living independently in the community. In mid-March the mother made a complaint to NDIA about the lack of response to the Internal Review request. As a result of making a complaint they were offered a planning meeting. The mother was not made aware at any time that her Internal Review request was being treated as an s48. The planner themselves stated at the planning meeting that they were not aware prior to the planning meeting that an Internal Review request had been submitted to NDIA. An advocate had to explain that NDIA were withdrawing the Internal Review and offering an s48 in it's place.

The mother accepted the s48 and withdrew the s100 in order for the plan to be amended within a short time frame. The resulting plan did not have enough funding for the participant to be supported 24 hours per day, which was supported by all the documents submitted to the planner. The decision could not be appealed at the AAT and another Internal Review was required to ensure that the participant had

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sufficient supports in her plan to ensure she could safely live independently. The Internal Review has not been priority actioned as of October and the participant remains at risk.

We also have evidence of NDIA staff and Contact Centre staff actively encouraging people to take an s48 instead of an Internal Review and in doing so providing false and misleading information. Information provided to participants by the NDIA includes:

- An Internal Review takes so long that people are better off asking for, or agreeing to, an s48 review. We are aware of cases where the s48 review was agreed to but still hadn't been actioned for over 2 months.
- You would only do an Internal Review if you wanted to then go to the AAT. This is incorrect as it is still a choice as to whether someone goes to the AAT or not.
- There is no point doing an appeal to the AAT unless a person wants to set precedent because the AAT takes so long and there will be a financial cost to the person. There should be no cost to the person going to the AAT, a costs would only be incurred if they wish to take it through to the court system.
- There is no benefit to completing an Internal Review. This is incorrect as you get a detailed explanation of the Internal Review decision and why requests have been granted or denied which is helpful in terms of understanding what additional evidence may be needed. Plus, you have the right to appeal at the AAT, which can be a quick process if settlement is reached with the Early Resolution Team.

This information is factually incorrect and again is not procedurally fair, denies natural justice and further disempowers people.

We have experienced a situation where the Internal Review was kept open while the s48 review proceeded, and NDIA advised they would finalise the Internal Review if the participant were unhappy with the outcome of the s48 review. The legislation does allow an Internal Review to apply to a varied decision. What is not clearly articulated in the legislation is that a new or amended plan is considered a varied decision. The legislation needs to be amended so that it is clear that an Internal Review can remain in effect if a person is offered a new or amended plan through a review process. This will ensure that people have access to their statutory right to appeal if a new or amended plan is in place.

**Recommendation 14:** Amend the legislation to ensure it clearly states that an s100 Internal Review can remain in effect where a plan review or amendment is being offered.

### Advocates Authority to Act and consent

The NDIS Act acknowledges the role of advocacy in representing the interests of people with disability, in particular recognising and respecting that advocacy supports people with disability by:

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- Promoting their independence and social and economic participation; and
- Promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and
- Maximise independent lifestyles of people with disability and their full inclusion in the mainstream community<sup>1</sup>

However, in practice the ability of an advocate to act on a person's behalf to ensure they have choice and control is not supported. From the beginning of 2019, it has been increasingly difficult for nominees, family, and advocates to seek information, get advice and act on behalf of the person with a disability even though consent is present. This includes where informed consent has been provided or the person with the seeking information is a nominee but not a legal guardian.

Advocacy agencies are independent and accredited. The processes they have in place to seek consent and authority to act are recognised across all government systems. There has never before been such widespread issues with seeking information or acting on behalf of a person where an organisations consent has been provided. Advocates are facing many barriers to acting on the behalf of participants where consent is provided. This includes submitting Internal Reviews, requesting s48 reviews, or submitting requests for changes in nominees amongst many other issues.

The legislation has general principles guiding to actions of people who may do acts or things on behalf of others (Section 5) however, there is no mention of advocates in this section. Section 100(2) of the legislation specifies that only persons directly affected by a reviewable decision may request the CEO review that decision. There is no recognition of the right of a participant to have an advocate act on their behalf in this respect. By ensuring the legislation acknowledges and supports an advocates right to act, advocates will better be able to complete their advocacy role supporting participants and potential participants. This will reduce delays in the provision of advocacy, the resolution of issues with NDIS and result in better outcomes for participants.

Additionally procedures and processes should ensure that NDIA staff understand the role of advocates, and their authority to act. Consent process should be streamlined to ensure that advocates have timely access to information, and can act on the behalf of participant to meet specified deadlines without undue burden around proof of identify and authority to act.

**Recommendation 15:** Section 5 and 100(2) of the legislation be amended to reference a person right to have an advocate act on their behalf and include a definition of independent advocacy.

### Access Requests - timelines for receiving complete requests

Many people who contact NDIS about Access are not being provided with adequate information about what they need to include with their application. When Access

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<sup>1</sup> NDIS Act 2013, Part 2, 4(13)

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Request Forms are received by NDIA the person is being told they have to supply further evidence within 28 days as per Section 26(2) and 26(3). Often there is no specific advice about *what* evidence is required. Many people also do not realise that they can request the deadline be extended. 28 days is often too short a timeframe for people to supply additional information for various reasons including:

- People may need to seek reports or assessments from health professionals where there are waitlists
- People may be working and find it difficult to attend an appointment within the specified deadline
- The time it takes for health professionals to produce reports can be longer than the 28 days

Additionally people may need to undergo assessments or examinations such as OT Functional Capacity assessments, in order to provide sufficient evidence to NDIA of their eligibility. Because in practice NDIA does not specifically request the person undergo an assessment, but does request further information, the 28 day time frame applies.

Where a person has not been able to supply the additional information within the 28 day timeframe (or a longer specified period) the person is taken to have withdrawn the Access Request. This means they need to contact NDIA to request a new Access Request Form, and recomplete the form, to apply again.

**Recommendation 16:** Amend the legislation to increase the timeframe for submitting additional information or reports to 3 months before the access request is taken to be withdrawn.

### Nominee Safeguards and Conflict of Interest

PWdWA have experienced instances of nominees who do not act in a way that is consistent with the views of the participant. The trend of service providers with a clear conflict of interest appointed as nominees without independent oversight is also concerning.

Part 5 of the legislation relating to nominees does not support the principles of choice and control for people with disabilities. The legislation positions the plan nominee as a substitute decision maker with no requirement to take into consideration the participants wishes. In practice, a nominee may be needed where a person has the capacity to make their own decision, but has no ability to communicate these decision to the NDIA without support. However once the nominee is appointed they can make decisions which the participant may not agree to or with. There is also no requirement to have a specified time for nominee appointments to be reviewed.

Section 78(5)(b) states a plan nominee appointed by the CEO can only manage the funding of supports under the participants plan if the nominee considers that the participant is not capable. Section 80, which outlines the duty of a nominee to a participant, specifies that the nominee can do, or not do an act, if they believe it

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promotes the personal and social wellbeing of the participant. Section 80(4) further states only that the rules *may* require nominees to engage in supported decision-making, and have regards and give appropriate weight to the views of the participant.

The appointment of a nominee can be on the initiative of the CEO (s86(2)(b) and s87(2)(b)). In appointing a nominee the CEO only need to *consider* the wishes of the participant (s88). The CEO also may cancel the appointment if requested to do so by participant but there is no requirement for them to do so (s90)

The way the legislation is written does not support the autonomy, choice and control of participants. There is no independent oversight in determining if a person is not capable of doing an act. The legislation in effect supports best-interest substitute decision making which contravenes the United Nations Convention on the Rights of People with Disabilities. We have had to support a participant to request the removal of a nominee who refused to assist them to request an Internal Review of their plan. Even with signed consent for the advocate to act on the person's behalf, NDIA stated they could not remove the nominee, and that the nominee would be required to submit the Internal Review. This is a clear example of the inherent flaws in the current legislation.

Additionally there is no requirements for nominees to identify any conflict of interest that may exist. We are aware of service providers being appointed nominees, and parents of adult participants being appointed without confirming the appointment with the participant. There is a clear conflict of interest when a service provider takes the role of a plan nominee and therefore has control over things such as:

- Requesting a review for additional funding
- Appointing their own service in the management of the funding for supports

Given the obvious flaws in the legislation as outlined above this open up the use of nominees to abuse and places participants at risk. We understand that in some circumstances the service provider may be the only support in a participants life who are able to act on their behalf when needed. However, there needs to be clear guidelines on how to manage, minimise or eliminate conflict of interest.

**Recommendation 17:** Amend the legislation in relation to nominees:

- remove the power of the nominee to act or not act based on their opinion of whether doing or not doing an act promotes the person and social wellbeing of the participant.
- require a nominee to carry out the views of the participant unless it is independently determined the participant is unable to make decisions even with supported decision making.
- require a nominee to undertake supported decision making where required, and have regard to the views of the participant

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- require nominees to declare a conflict of interest and where it exists provide at minimum yearly reports as to how any conflict of interest has been managed.
- require the appointment of nominees to be reviewed no less than every 3 years.
- require NDIA to include appropriate funded supports in plan to help minimise and eliminate the need for a nominee where conflict of interest exists e.g. fund supported decision making

### Recognition of legal guardianship and no requirement for guardians to be appointed

Section 4 of the Act states that people with disability should be involved in decision-making processes that affect them, and where possible make decisions for themselves. It also states people with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity. Additionally Section 17 states that people with disability are assumed, so far as is reasonable in the circumstances, to have capacity to determine their own best interests and make decisions that affect their own lives.

PWdWA has seen a disturbing trend of NDIA staff telling parents, and service providers that Guardianship orders are needed when a person may require a nominee or cannot sign a service agreement. There should be an inherent presumption of capacity of people accessing the scheme. Guardianship orders restrict the rights of participants and are far more restrictive than the option of a nominee. They should be considered a last resort option for anyone with a disability and only pursued after less restrictive options such as a nominee and support decision making are explored.

The legislation needs to be clear that a participant does not require a legal guardian where they require someone to act on their behalf in relation to NDIS matters.

Where a legal guardian exists, which includes the parent of a person under the age of 18 or a legally appointed substitute decision maker (for decision relating to funded supports), there should be no requirement for that person to be appointed as a nominee to act on the participants behalf. Requiring them to register as a nominee is an additional hoop to jump through when they already have legal authority to act on the persons behalf.

**Recommendation 18:** Amend the legislation to provide a clear definition of a legal guardian and recognise the authority of legal guardians to act on participants behalf. Ensure the legislation is clear that Guardians are not required if a person is unable to act or make their own decision.

**Recommendation 19:** Amend the legislation in the nominee section to refer back to Section 17A (3) (b) recognising capacity. Refer to principles of supported decision making in the legislation and rules to support capacity. Refer to relevant state legislation in each jurisdiction on capacity.

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### Use of language around reviews

The language used in the current legislation around s48 reviews and s100 Request for a Review of a Reviewable Decision (Internal Review) is problematic and confusing for people. Many people who contact PwDWA do not understand the difference between the s48 and s100 review types. There is also the added complication that the end of plan review and any unscheduled plan reviews are both technically s48 reviews (albeit the end of plan review is at the CEO's request).

**Recommendation 20:** Amend the legislation to call an s100 Review of a Reviewable Decision (AKA Internal Review) an Internal Appeal and clearly differentiate this process from a plan review.

**Recommendation 21:** Amend Section 48 of the legislation to define two types of plan reviews:

- Scheduled Plan Review – a review which occurs within 6 weeks of the end date of a plan and is initiated by NDIA
- Unscheduled Plan Review – a review which can occur anytime within the lifetime of a plan at the request of a participant or the CEO

### Setting Culture and Understanding at Board Level

The principles set in the NDIS legislation in Chapter 1, Part 1 and in Chapter 4, Part 1A are all sound principles, which can be linked back to the UNCRPD. Although our suggested changes to legislation would improve the scheme, there is a strong element of culture influencing how current legislation is interpreted. The Act emphasises choice and control yet the agency emphasises reasonable and necessary. The Act supports capacity and people's own expertise and situations to be supported, yet the agency emphasises external experts and the following of set plans with people feeling they are not heard and have no ownership of the plan.

The culture of an organisation is set by the Board and Executive levels through management decisions and how they engage. We believe the balance on the board is not right and the legislation does not give enough emphasis to lived experience of disability. The only criteria for the Board regarding disability is that a board member could have experience as a provider or user of services. There is currently no requirement for even one Board member to be a person with disability. The Independent Advisory Council do not make decisions for the agency and so should not be seen as a proxy for involvement of people with disability on the Board.

**Recommendation 22:** That the section of legislation relating to Board Members be amended to mandate 50% of the Board to be people with disability.

### Section 3 – Feedback on proposed Participant Service Guarantee

The interface, feedback and experiences shared by the individuals seeking access, or already accessing the NDIS is pertinent to the development of the NDIS Participant Guarantee and the seven principles guiding this.

The responses provided in this section has been informed by the feedback we have received from our members, the community and the experiences of the people we support.

#### Principle 1

*Timely: The NDIS process is easy to understand and use. Decisions about access, planning, and review happen quickly.*

This principle is key to a number of sections in the current NDIA Act 2013 (s15, s17a, ss21-26,ss31-33,s38,ss47-48,ss89-91,ss99-103).

#### *Ch (2) Section 16 states*

“in a manner that they can understand The Agency must use its best endeavours to provide timely and accurate information to people with disability and other people in order to assist them in making informed decisions about matters relevant to the National Disability Insurance Scheme”

#### *Ch (1) Section 4 states*

“People with disability should be supported on their dealings and communications with the agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs“

The feedback from individuals regarding the time taken to receive responses to request to access the scheme, planning meeting, reviews, call centre responses and change of circumstances has highlighted the continued concerns and dissatisfaction by large numbers of participants.

Specific issues that relate to the legislation are discussed in Section 2 of this submission. In addition to these issues, there are also problems with the timeliness of day-to-day process and practices within the NDIA.

#### *Uploading of information and response to email enquiries*

The time taken for participant information, such as reports and advocacy consent forms, to be added to a participant’s files can be excessively long. Participants report information provided to NDIA getting lost, or being received after it was required for

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planning or review purposes. In some cases NDIA has acknowledged receiving advocacy consent over a month after it has been provided by email, and after the persons case has been closed. The lengthy delays in processing and responding to emails and the submission of information means that NDIA may not act as required under the legislation or participants may not have all the relevant information considered when NDIA makes a decision. It also means advocates are unable to progress a participants issue, which could include ensuring they have been able to submit an Internal Review within the required timeframe

### *Responding to and actioning complaints with 21 days*

Another common complaint by participants and their carers and family, is the lack of response and action to complaints. NDIA advises that it will respond to a complaint within 21 days. In some cases the NDIS Contact Centre have failed to record a complaint. Contact Centre staff are also unable to provide information on where a complaint is sitting, whether it has been actioned and cannot effectively escalate it.

In other cases where complaints have been made it has taken in excess of 2 months for complaints to be responded to or actioned and in some cases no response is ever received. PWdWA assisted one person who had been waiting 95 days for their complaints to be addressed. In many cases where PWdWA have assisted people to follow-up on complaints, these are usually in relation to urgent matters where there is a risk to the participant.

### *Issue with quality and timeliness of information from NDIS Call Centre*

In June 2018 the NDIS outsourced the management of it's National Contact Centre to Serco Citizen Services Pty Ltd (Serco). The NDIA stated that the outsourcing of the central contact centre would ensure it could provide fast, accurate and effective advice to callers.

While we acknowledge that the wait time for the NDIS Contact Centre calls has significantly decreased since the outsourcing, the transition to Serco managing the NDIS Contact Centre has resulted in a multitude of other issues being experienced by both advocates and participants/potential participants. A clear indicator of the dissatisfaction from participants regarding the NDIS Contact Centre is seen in the results of the PWdWA 'Your NDIS Experience' survey. The survey has been open since the beginning of May 2019 and common and consistent trend in the feedback being provided is around issues with the call centre.

Many of the 'Your NDIS Experience' survey participants specifically spoke about the frustration of not being able to get the answer they needed to resolve their issue. They state that NDIS Contact Centre staff do not have access to the required information, cannot give them a straight answer, and are unable to offer a transfer through to someone who can answer their enquiry. Advocacy WA reported that in 41

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of their cases involving NDIS, clients had trouble when contacting the NDIS Contact Centre.

In many cases call centre staff are unable to find the required information to assist a person with their enquiry, claiming they do not have access to it or it does not exist. This results in delays for people trying to navigate the system.

A common trend in the feedback from the PWdWA 'Your NDIS Experience' survey was around call backs from the NDIA. A number of survey participants spoke about the NDIA Contact Centre staff being unable to answer their questions and promising the person a call back from the appropriate NDIA staff member that never came.

"No return contact after contacting NDIS call centre for help multiple times."

"It is absolutely impossible to contact anyone from NDIS. You can phone and email multiple times without any success."

Your NDIS Experience survey 2019

### *Process is not easy to understand and use*

The general feedback from participants entering the scheme, accessing the scheme and navigating the scheme has been that the processes and procedures are bureaucratic, complicated and "clunky".

Feedback from Consumers of Mental Health WA (CoMHWA) in consultation with people with a psycho-social disability has been that participants who may be eligible need support to go through the accessibility process. Many people in this cohort have significant cognitive episodic impairment and without social or informal supports are unable to traverse the application process. Homeless individuals, young people with mental health issues who are away from their family all have limited supports. Without supports the application process is very onerous and people are falling between the gaps. Having to not only understand and navigate the access process, the capacity to provide all the documentation required is virtually impossible without support. There is limited consideration and flexibility in the current processes to support these situations

CoMHWA noted that those individuals that reported positively of the NDIS, were those individuals that had intensive support to learn about the NDIS and had dedicated support to help them to apply and navigate the whole process. Some of these individuals had support via the "WA Hostels Project in that commenced in 2016. [*Building New lives: Bringing the NDIS to Psychiatric Hostels Perth Trial site WA*]. Others had very strong support from family or friends.

These individuals were very supportive of the NDIS and the "new life" it had given them. Those individual that struggled and were challenged by the NDIS process were those who lived independently and had few family members or carer supports.

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For those participants who have applied, there is no system in place to monitor the progress of the application. This causes anxiety and stress for the participants. The feedback has been that this has resulted in people becoming unwell both mentally and physically.

“I was very Proactiv and took time off work to study in detail the NDIs, this is what helped me immensely, If I had NOT done this I would NOT have been able to even Understand the Jargon used, This is a Big Problem for CALD group of people , where Language and Culture are a huge barrier.”

“No information sent out by NDIA prior to meeting. Information sessions were not advertised - found out about them by accident/facebook - this is totally inappropriate. If person with disability had to rely on NDIA giving them information they would be in the dark. Incorrect and vague information given out by various people at the seminars. Very confusing “

“I thought I understood preparation and pre-planning and had done it thoroughly. However this didn't prepare me for the different terminology so that in the end I didn't realise what I was asking for or when I did ask it was misunderstood. I have had to have a light touch review done on the 1st plan and the other one which was supposed to be just a straight transfer from WANDIS was approved on 1st April and still not operating fully. I asked for a light touch review but I think this has been ignored and they are still trying to get everything straight. I couldn't link both plans to My Gov because they didn't have me down linked with both sons. Then the second one was duplicated and I have had to start over with that. It isn't the planner's fault it's all just a misunderstanding not helped by the fact that you have to go through the generic "enquiries" email site and get someone different every time.”

Your NDIS Experience Survey 2019

At a recent peer group meeting a lady shared her story that involved the process of her first planning session with the NDIS planner. She went well prepared as per the recommendation in the NDIS planning tools on the NDIS website. She felt very stressed and anxious when attending her meeting not understanding the process. Despite attending the local NDIS information session in her local community she still felt very unsure of what she could expect and request in the meeting stating “*I don't know what to ask for*”. She has a vision impairment and despite the planner knowing this there was no provision in the process that provided her with appropriate access to information discussed. She was frustrated that “*blind people [are] expected to deal with paperwork.*” After the meeting, the plan she received did not reflect her requirements. She had to go through the review process however, this was not adequately explained to her other than being advised that the whole plan will be reviewed and this may affect some of the other areas in the plan. This made her feel nervous and anxious about going through a review process that took 5 months. Despite eventually having a plan that she is now happy with (although not in an

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alternative format) she said the processes and procedures caused her undue stress and anxiety the process has made me feel *“more unwell than I have ever felt.”*

### *Need for Support to understand and utilise plans*

The current format of NDIA plans means that participants can be unsure about what supports are available in their plans. We acknowledge that NDIA want to ensure as much flexibility in plans as possible and this is why line items or specific supports are not always specified in plans. However many people are new to individualised funding, and the ability to take a lump funding amount and determine how it can be spread across required supports is not an easy task.

Key issues identified by CoMHWA and PWdWA about the difficulty participants had in utilising their plans included:

- Lack of knowledge of how to go about using their plan and making the right decisions.
- Lack of guidance around choosing support providers – just given a list of providers and unsure what the next steps were.

A parent shared that she was fearful to use the funds allocated in her sons plan because she didn't understand what it was for. She had no support coordination in her plan and had been encouraged to self-manage. Despite attending a number of workshops provided by NDIS, LAC Partners and other service provider workshops she felt more confused and after 6 months had still not used anything in her plan accept the therapy services which she had previously been accessing in the state system. Her comment: *“make it simpler.”*

### *Time taken Providing Approved Plans*

The consistent feedback from individuals and families is that the time it takes to get responses about all processes within the access, planning and review stages from NDIS is inconsistent, frustrating, stressful and bureaucratic.

Despite there being a specified timeframe of 7 days for providing plans once approved, delays are still experienced. NDIA needs to ensure that procedures/processes support the effective implementation of legislated timeframes. There must be flexibility in providing plans in appropriate forms within the 7 days, including via email as well as via post and the portal.

A parent contacted PWdWA because he was unable to access a copy of his daughters approved plan for 3 months due to issues with accessing the NDIS portal. It was only after multiple calls and complaints that he was able to access the plan. When they were finally able to view the plan, they realised that there was insufficient therapy supports funded. At this stage, it was too late to request an internal review. An unscheduled plan review was requested however it has been over 5 months and the plan review has still not taken place.

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Additionally, the introduction of LAC partners has seen a new step before plans reach a delegate for approval. The role of LAC partners was envisioned to be a pre and post planning support, not a plan builder. The LAC should be supporting people to prepare for planning meetings, thinking about what information is needed, collecting evidence, and helping the family determine what their supports needs are. Currently LAC partners are building plans and sending them off for approval. This creates a conflict, as LACs focused more on reasonable and necessary rather than understanding the participant's needs. Ideally the LAC should be supporting the participant at a planning meeting with the NDIA delegate who will build and approve their plan. This ensures that there is no miscommunications, and minimise the need for extended back and forth between LAC's and delegates.

**Recommendation 23:** A new principle in the Participant Service Guarantee should be included:

'Easy to Navigate: The NDIS process is easy to understand and use.'

**Recommendation 24:** The 'Timely' principle needs to include guarantees for participants around timeliness in accessing information and responses outside of specific legislated actions such as:

- Access to timely and accurate information from NDIA front of house and call centre staff
- Timely action on day-to-day processes such as uploading documents
- Processes and procedures which support the implementation of legislated timeframes and quick responses

**Recommendation 25:** The Agency adopt an Application Progress Notification System to allow applicants to track progress, similar to online deliveries.

**Recommendation 26:** Adequate numbers of LAC partners to be in place, and funding of Support Coordination must be made available to participants to assist with the understanding and implementation of their plans.

**Recommendation 27:** As part of the participant guarantee simple decision support tools to assist participants with processes such as access, planning, plan implementation and reviews are provided and made available throughout all points of the NDIS journey.

### Principle 2

*Engaged: The NDIA engages with people with disability, their family, carers, and other support persons when developing procedures and processes.*

This principle is key to a number of sections in the current NDIA Act 2013

(NDIA Act 2013 ss4-5, ss13-17a,ss86-98,s144).

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The ultimate engagement with people with disability in deciding on direction for the agency is by having people with disability as significant stakeholders on the NDIA Board.

To enact this principle the agency and DSS need to understand and utilise co-design appropriately. PWdWA has done a lot of work on developing a co-design guide and toolkit through working with a diverse group of people with disability.

### Summary of co-design

Co-design is a tool that when done well, changes the provider-client relationship. It's more than sharing experiences, or gathering responses through consultation. Codesign recognises that users are 'experts' of their own experience, and are central to the design process when identifying the problem, and exploring and developing solutions. The 'co' goes all the way to deciding which solutions will be taken up. 'Design thinking' can be part of the process to test and prototype models or solutions before making decisions.

Co-design is not a replacement for consultation, and often a prototype or draft developed through co-design will go out for consultation before coming back for further change. The co-design process is a way of feeding in lots of diverse information and experiences to delve deeply into an issue and design solutions.

As a peak consumer representative organisation co-design resonates with the mantra 'Nothing about us, without us'. PWdWA wanted to know what co-design meant for people with disability. We brought together a diverse group of people to explore co-design and co-design our own guide and toolkit on co-design.

According to the People with Disabilities WA co-design project group the key success factors are:

- Active and meaningful involvement – everyone is taking it seriously and has equal power.
- Involvement of people with a diversity of experiences– all experiences are valid.
- Willingness to share – trusting in each other to listen and contribute.
- Purposeful collaboration and partnerships – knowing why you are involved, having a shared objective.
- Being inclusive, flexible and open minded – listening and being prepared to change.
- A cultural shift that values the co-design principles – decision makers trusting the process.

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The role of facilitation is an essential component of a successful co-design project. Facilitators provide ways for people to engage with each other, share insights and test out new ideas. If an organisation or department is showing they are equal partners with consumers, having an independent facilitator keeps the power relationships balanced.

Currently the NDIA uses advisory groups and some co-design to develop new processes and procedures, however the group members are not necessarily a diverse mix representing the participants. More often people are hand picked and then asked to keep discussion confidential.

For the engagement principle in a service guarantee to work, there must be a commitment to using co-design wherever possible as well as being transparent and providing feedback.

**Recommendation 28:** The 'Engagement' principle needs to include a commitment to true co-design, with diverse representation in co-design groups.

**Recommendation 29:** Transparency of the people involved and process and /or problems being worked on must be included in the 'Engagement' principle.

### Principle 3

*Expert: NDIA staff have a high level of disability training and understand the impact particular disabilities have on people's lives. They understand what supports are most effective for a person's disability.*

The quality and expertise of the NDIS Planners and the LAC planners is a regular conversation shared at peer groups, on social media groups and as part of the PWdWA survey responses for NDIS Transition and interface issues. This was discussed with the co-design group at PWdWA which is a part of the NDIS Transition and Interface systemic project. After analysis of the PWdWA survey a consistent theme is the quality of planners in NDIA.

The feedback from individuals and families has been that the quality, experience, expertise and qualifications of the planners varies markedly from planner to planner. This includes professionalism of the planners in engaging with people from the very outset of the planning session. Planners often came to planning meetings unprepared, they have not read the documentation previously provided by the individual and their family and are under a very tight time schedule. The experiences shared by participants, their families and supports about the planners the planning process and the outcomes demonstrates the lack of consistency, knowledge, understanding and transparency. The feedback is that people feel they are at the mercy of the planner on the day to try and ensure that they get a plan that reflects their needs. Many comments provided by people experiencing the planning process state they find the process demeaning, disrespectful, insulting, unaccommodating, judgmental and confusing.

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A participant shared the experience of her first planning meeting with NDIS. She has a vision impairment and was born with the condition. Her entire life was about building her independence, living and accessing her own community. She explained that she had never received any services from the state system but was required to get an NDIS plan in order for her to remain working in supported employment. She attended her NDIS planning meeting with all the documentation about her disability. The planner did not ask for any documentation. In the meeting the participant clearly described her life and the reason for the plan which was one funded goal to remain working at the supported employment facility. The plan was completed and sent to the participant. The plan she received described her as disabled blind person requiring support to maintain her home and access the community as well as the support for her employment. She was so upset by the plan she rang the planner and asked to remove some of the wording in the plan and the added supports she didn't require. The planner did not accommodate her request. The participant said of the experience: *"I have never been made to feel so disabled and be so defined by my blindness."*

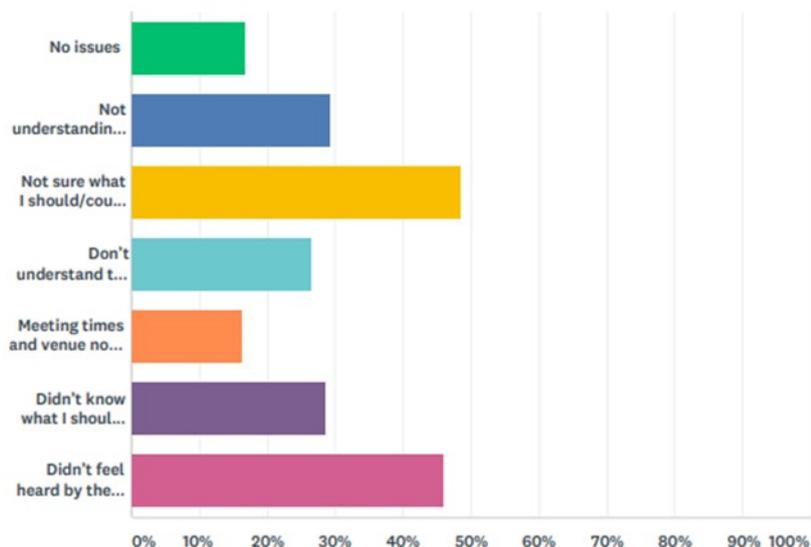
The planners often use NDIS speak that families and individuals do not understand and people walk away thinking they have been understood and have what they need in their plan but end up with a plan that looks completely different. This very common theme is reported as an issue, with 45% of survey respondents saying they did not feel heard by the planner and 48% saying they did not know what they should be asking for.

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### Your NDIS Experience

Q7 Have you experienced any of the following issues with the NDIS planning process? (please tick as many answers as applicable)

Answered: 233 Skipped: 79



| ANSWER CHOICES  | RESPONSES  |
|---|------------|
| No issues   | 16.74% 39  |
| Not understanding the preparation and pre-planning requirements for the meeting | 29.18% 68  |
| Not sure what I should/could ask for?   | 48.50% 113 |
| Don't understand the process  | 26.61% 62  |
| Meeting times and venue not providing flexibility                               | 16.31% 38  |
| Didn't know what I should bring to my meeting                                   | 28.76% 67  |
| Didn't feel heard by the planner  | 45.92% 107 |
| Total Respondents: 233  |            |

Many clients accessing Individual Advocacy comment that the planner did not seem to understand the needs of the person with a disability, especially where they were complex. The NDIS planners understanding of complex appears often to be limited and finite. Although there is an acknowledgement by NDIA there is a need for a “complex support needs pathway” that supports people with more complex support there is little acknowledgement that complexity for clients can be more than the pointy end situations that may involve mental health, homelessness or justice interface.

Complex supports could involve:

- multiple service providers,
- parent or carer capacity,

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- Families who have other members in the same home with disabilities or mental illness.
- Refugee families who have experienced trauma
- Families with English as a second language from CALD backgrounds
- Individuals who have complex needs with communication or behaviour
- Multiple areas of support within a plan.

An example of the inability of planners to understand complex needs can be seen with a transition from state-based funding to the NDIS. The state-based funding plan had the incorrect dollar amounts attached, but provided clear information about the participants need for behaviour support and 2:1 supports. There were therapy reports and information provided for the planning meeting which all supported this as a reasonable and necessary support. The planner failed to review the content of the plan and the evidence of need and instead look at the dollar amount in the plan and based the NDIS plan off that. The result was a plan that only had half the required funding, leaving the participant without safe access to the community, limited support to develop his independence and the family without a safe home environment

The other concern raised by participants is planners having little or no understanding of unique or complex communication needs for participants. PWdWA recently engaged with the deaf/blind community holding a workshop with them to understand the issues and challenges they are experiencing in the transition to NDIS. The feedback was greatly concerning in that the majority of people felt they were not understood by the planner. The need for specific interpreters was denied. People had turned up to planning meetings and interpreters were not booked. Planners suggested plans could progress by writing down questions and answers on paper.

The co-design group comprises members with a broad spectrum of disabilities. The strong feedback was that *“people with a disability are the experts in their disability and that planners needed to treat them as such.”*

The co-design group felt that NDIS planners need to have a knowledge of disability and that participants should be told the background qualifications of the planner to provide them with confidence. The planners should also have around broad training around different disabilities for then to understand what is reasonable and necessary. The group also felt that the questions that planners ask are too generic, irrelevant in some cases and closed. The planners don't explore the answers provided by the participant.

For example, a participant explained that in her planning meeting she was asked generic questions such as “do you sleep all night?” and “How often would your disability preclude you from sleeping?” The young lady has mental health and autism. Her anxiety disrupts her capacity to sleep resulting in her not being able to function during the day and staying in bed. She couldn't quantify that to weekly, fortnightly or monthly. The planner then rang her after the plan had been completed

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and finalised congratulating her on receiving the finalised plan only to find out the therapy support she required which was the purpose for her joining the NDIA was not supported. She felt disregarded and very disappointed about the entire planning process.

“Many aspects of the NDIS are wrong and there’s no consistency and a severe lack of training in what can be included and is available”

“My daughters latest plan which started February 2019 was the easiest and most pleasant process. Her first plan and the process brought me close to a mental breakdown “

“Specialist reports and recommendations on hours of assistance required not being considered”

“Major items left off the plan such as wheelchair and host family funding!”

“Planner read from a script had none/little understanding of conditions, was condescending, answered questions for me, when asked not to, rushed the meeting, would not read supporting documents, said no everything without reason, provided NO advice/suggestion/ideas, might as well have filled out the computer program ourselves “

“Didn’t get all I asked for. As they forget to put some things onto my plan that was asked”

“Planners not being prepared. Don’t send an email asking participants to send in documents well beforehand if you are not going to read them. It seemed they did not have enough clerical support too.”

“The last planner was wonderful, the previous planner in 2017 was dreadful, dismissive, condescending and elitist”

Your NDIS Experiences survey 2019

Feedback from CoMHWA peer groups described these issues and concerns about planners and the process:

- Participants expressed difficulty with the planning process; not know how to articulate their goals, what to apply for. Planners did not always have a good understanding of the episodic nature of their illness. Visual activities and prompts could alleviate this.
- Peer Support at a planning meeting was seen as vital to assist the participant to keep on track. Planning meeting were often long.
- Participant found that there was a greater need for clarity by the use of example, so they understood what was meant. For example *Transport - eg smart rider; taxi vouchers or a support worker to take you to daily activities.*

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- Recognition and understanding of a participant's knowledge of their needs and wants. One individual reported on the difficulty in getting funding to train a service dog – she saw it as more cost effective and sustainable than a support worker to access the community.
- Carer's expressed the need for their role to be valued (with appropriate boundaries) - many of the people they cared for in this cohort (depending on their cognitive state) were not always able to express what their actual needs were.
- Under- utilization of plans used as evidence of support not being needed , rather than due to episodic nature of mental illness.

**Recommendation 30:** Include in the principle on 'Expert' that people with disability, and their families and carers as appropriate, have expertise in their own disability, functionality, and situation. Include that planners will listen.

**Recommendation 31:** NDIA and LAC partner organisations recruit more people with disability into planning roles, and staff receive regular training **from** people with disability with expertise.

**Recommendation 32:** Utilise peer champions to work alongside LAC Partners to get the message across in a consistent manner and support people to engage with and participate in NDIS application, planning, plan implementation and review processes.

### Principle 4

*Connected: The NDIA works well with governments, mainstream services (such as health, education, justice services), disability representative groups and providers to ensure people with a disability have coordinated and integrated services.*

This principle is key to a number of sections in the current NDIA Act 2013 (s59,s121,s144,s148(4)).

The transition to the NDIS has created challenges in the interface between government departments, existing services, mainstream services and providers in the sector. As participants transition into the NDIS many of the services that they have received from block funded programs such as HACC, PHaMs, PIR, RDA, Continence support, Transport, CAEP and medical and mental health services have now been included in their plan. Many participants have been in receipt of these block funded supports for long periods and have never had to negotiate service contracts, sourcing providers and navigate service systems.

The government and mainstream services are struggling to support people to transition across to NDIA providers who can offer the services and support that people require. An example of this is in the Geraldton area where a large number of individuals have managed with supports from the HACC service that has been provided through the Geraldton Regional Hospital. Most of the recipients are living

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alone without informal support to assist them to apply for access to the NDIA. The hospital HACC coordinator was tasked with assisting over 80 people to apply for access to ensure that people still continued to receive a service. The coordinator stated that she was overwhelmed with the task as they had not received any additional resources to assist them nor was she able to assist people to get the necessary documentation required due to her limited time. The greatest concern was that people would have services ceased and be without any support. This situation did not demonstrate collaboration or a coordinated approach to support these individuals as their area rolled into the NDIA.

Another example of concern is people who are requiring a plan to be developed with NDIS so that they can leave hospital or those that are long term in rehabilitation unit and require a plan to leave. Collaboration between the health /hospital system, the NDIA and service provider requires coordination to bring the various parties to the table. Where does the coordination come from? The pressure is put on the families of the individual to try and navigate the various systems. Often families are not in a position emotionally and mentally to be able to do this. The hospital system has pressure to free up beds if people are not deemed unwell. Pressure is placed on families to take their family member home even though that may not be an option or explore nursing home /short term placements. A collaborative approach is required to ensure that a plan is developed for the person that reflects their needs, support and long term security.

Within the mental health services as reported by CoMHWA it is estimated that only 25% of people being supported through Commonwealth psychosocial programs have transitioned to the NDIS in Western Australia. However Transition Support Funding is only committed for 19/20 financial year. People who are not in the existing Commonwealth or State programs transitioning to the NDIS have lower successful access requests than those with program entry (50% ineligible compared to average of 33% ineligible). Individuals who were Commonwealth program participants on or before the 1<sup>st</sup> July 2019 do not have the continuity of support arrangements and need assistance to access alternative supports. There are an estimated 79,991 individuals affected by severe mental illness in any year in W.A. This creates significant unmet needs for alternative support arrangements and for navigating alternative supports.

The disability sector is struggling with the volume of participants seeking service, this is particularly evident in the therapy area. A family reported that they have a large package in their plan for their son for therapy however they are unable to find a service provider to provide the services. Many therapy providers have waitlists, which means participants are waiting long periods to receive a service.

The country and regional areas are impacted by and limited service providers. A parent in living in Hyden with three adult children each with an NDIS plan described the challenges they have experiences to implement the plans. They have to travel 4

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hours to receive hydrotherapy services. They have one therapy provider that is 1.5 hrs. away in another town and has limited capacity. The parent has had to self-manage the plans and recruit and train her the support staff. The availability of support staff is limited as most have to travel from outlying farms or neighbouring towns and some travel 2 hours to get to work to complete a shift.

The health/hospital in country areas is often the only therapy provider in the town but once a person has an NDIS plan these services are no longer available and people have to travel to Perth or the closest larger town to receive services. This is particularly problematic for people who are needing assistive technology that requires OT /therapy oversight and approval.

**Recommendation 33:** The 'Connected' principle in the Participant Guarantee needs to include that the NDIA educate other agencies and services of its role, and provide pathways to community and mainstream services. The NDIA staff and LAC partners must be knowledgeable of complimentary services and encourage their use as well as alternative services.

**Recommendation 34:** In particular 'Connected' must include greater awareness and education targeted to health professionals to improve quality of evidence provided to potential participants.

### Principle 5

*Valued: Participants, their families, carers and other support persons feel valued in their interaction with the NDIS, and know where to go if they need assistance.*

This principle is key to a number of sections in the current NDIA Act 2013 (S4, s5, s17a).

Section 4 (3) states:

“People with disability and their families and carers should have the certainty that people with disability will receive the care and support they need over their lifetime”

The feedback from the PWdWA survey repeatedly highlights that participants, their families and supports do not feel valued, heard, respected in their interactions with the NDIS.

There has been lots of feedback from individuals and families about how they feel and were made to feel during the process

“There are some employee who are brilliant, but there is a massive disconnect between frontline and HQ, there is too much support for poor staffing, the whole process of complaint and review unduly disadvantage the participant, there is little to no advocacy available and the delays are outrageous. I am concerned for the other participant who do not have a good support network / advocate for them, as I believe they would be bullied and taken advantage during the process. The staff from the NDIS are not doing a favour, it is not their money that is assisting participants”

Your NDIS Experience survey 2019

A parent from a peer support meeting shared her experience with the NDIS. She said it had made her feel like she was a child being chastised for requesting support for her daughter. She explained that the planner shook her finger at her when she requested a mentor for her teenage daughter so that she could access social activities without her mother. The planner shaking her finger replied that was not a reasonable request as that was the responsibility of the parent.

The feedback and responses from peer groups and the survey has been that people feel intimidated and feel they need to justify their requests by the processes they have to encounter in the scheme. There is little acknowledgement of the commitment that families have for their loved ones and the time that they dedicate to their care and support. Often people have stated they feel that they have to go into the meeting “cap in hand” hoping that their story is bad enough to warrant the support they require.

The experiences highlighted under Principle 3 are also relevant here. The NDIA need to acknowledge, respect and value that people with disabilities are the experts in their own disability.

If people are to feel valued by their interactions with NDIS all processes and procedures need to reflect the rights and entitlement that participants have to the scheme and the staff representing the scheme engage with respect for the expertise that each participant and families bring about their disability needs. This is also part of the agency culture. If there are people with disability at Board and Executive level the modelling of people with disability as Valued is occurring

**Recommendation 35:** The ‘Valued’ principle must be supported by good information and advocacy provision that is adequately funded so people know where to go for support.

### Principle 6

*Decisions are made on merit: The NDIA acts in a transparent, informative and collaborative spirit so that participants understand why decisions are made.*

This principle is key to a number of sections in the current NDIA Act 2013 (ss99-103, s127(2)).

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Section 2 of this submission details issues faced around the lack of explanations provided for decisions such as access and funded supports and recommendations for resolving this issue. Recommendations made in Section 2 about request for further evidence are also relevant to this principle.

PWdWA are concerned on the use of the term 'merit' in this principle. Feedback from people with disability show the decisions are not transparent. Decisions are also often made based on the assumptions of the Planner of what is reasonable for the community without taking into account the persons individual and family circumstances. 'Merit' is defined as - deserve or be worthy of (reward, punishment, or attention). This is demeaning and devalues people with disability. The principles of equity and fairness should be what guides decision making.

**Recommendation 36:** Remove the term 'on merit' from the principle and replace with 'on principles of equity'.

### Principle 7

*Accessible: All people with disability can understand and use the NDIS, and the NDIS ensures it's services are appropriate and sensitive for Aboriginal and Torres Strait Islander people, people from Cultural and Linguistically Diverse backgrounds (CALD), LGBTQIA and other individuals.*

The language used in the NDIS is very bureaucratic and while easy English guides are available these assume people have access to technology and know how to use technology. People from cultural and linguistic backgrounds, families with limited capacity, and people living rough or homeless are excluded from accessing the scheme without external supports.

Once people have entered the scheme understanding the NDIS terminology in order to be prepared for the planning meeting is challenging for participants. The feedback provided in the PWdWA survey clearly demonstrates that language and terminology continues to be a barrier for participants, their families and supports.

In a recent workshop held by PWdWA with participants when describing how they feel about the NDIS language, words such as "confusing", "technical", "bureaucratic", "complex", "don't understand" and "disappointing" were used.

CoMHWA focus group participants also noted that people with psychosocial disability face additional barriers around language used by the scheme. They felt the language of the NDIS was in conflict with the language used in the Mental Health sector and as part of their previous mental health supports. In some circumstances they reported language as being a barrier. Additionally they noted that health professionals do not understand the requirements of the NDIS and that health terminology and NDIS language is at odds, especially in the mental health context.

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Communication, accessible information and providing environments where people feel safe to meet is crucial to engaging with Aboriginal and CALD participants. There needs to be a recognition that this cohort of people may not access to the relevant documentation required to access the scheme or justify supports in a plan. NDIS processes and procedures are very bureaucratic and gaining access via electronic means or completing forms may be well out of a person's capacity without significant supports. People requiring reports may not have the financial capacity to fund these.

The PWdWA systemic project has met with peer groups from CALD backgrounds and there is fear about the scheme and what it will or won't provide. Interpreting the NDIS plan is confusing and some families have not implemented their plan because they don't know how and are fearful that they may do something wrong.

People from cultural and linguistically diverse backgrounds have said that they do not understand the process and what is expected, and are often ill prepared for the meeting with the planner. Depending on the quality of the planner, families have left the meeting unsure of what has been put into their family member's plan.

Ethnic Disability Advocacy Services have indicated that a large part of their work is taken up with explaining and assisting people from CALD backgrounds to navigate the NDIS system.

In making sure that NDIA is accessible there also needs to be consideration given to people who require information and engagement in alternative formats, require supported decision making to engage with the NDIA or face cost barriers to access. There must also be consideration around accessibility for cohorts who were not previously connected to any services.

CoMHWA focus group participants felt that the Access process required significant IT resources, which may exclude individuals who are homeless, living rough or from very low socioeconomic backgrounds. They specifically felt the principle of 'Accessibility' as it is currently framed:

- Assumes that information is available & understood, where this not necessarily the case.
- Does not take into account cost barriers in the context of provision of evidence.
- Does not take into account "how up to date the information is". NDIS is evolving and no guarantee everyone is up to date, including staff.

NDIA also needs to recognise they must be flexible in their approach to things such as the location of planning meetings. For many participants, especially those with low mobility, young children or people who are caring for young children, attending an office for a planning meeting is not practicable. While there is technically the possibility for planners to attend the home, this option is rarely utilised. The alternative offered is phone meetings, which are often inappropriate, especially

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where the person requires supported communication. Planners have stated that the KPI's they need to meet mean there is a push for planning meetings to be over the phone.

Planners being required to meet with participants in their home if the participant wishes would help them to see and understand the participant's circumstances. It would also ensure that participants are in an environment where they are comfortable.

**Recommendation 37:** This 'Accessible' principle should be split to clarify 1. An accessible scheme for all people with disability; and 2. A culturally appropriate scheme that caters for First Nations people, CALD, LGBTQI+ in information and engagement.

**Recommendation 38:** To be accessible to harder to reach people the agency have outreach / mobile models of engagement to assist potentially eligible participants apply for NDIS to circumvent lack of access to appropriate IT facilities eg; people who are homeless, in hostels, or hospitals. That this is followed through with planning.

## Conclusion

The experience of participants and advocates with the NDIS has been one of dealing with many operational issues that are bureaucratic in nature and seem to be roadblocks that are meaningless. The concept and principles which underpin the NDIS are sound but it seems that in implementation there has been a fear of things like 'budget blow outs' and an emphasis on scheme sustainability which has led to tight and inflexible practices in some cases, or overly cautious interpretation and use of the legislation.

Through our first 5 years of the scheme we can see there are some useful tweaks to legislation that can be made to provide a smoother process and better alignment to the principles. Overall though there is a culture which is being promulgated in the scheme of having a tight hold on funds, and needing medical justification for any decision. For the scheme to truly become a mechanism for realising the potential of people with disability this culture needs to change to one of trusting people with disability, highlighting strengths and providing flexibility to reach outcomes.

Our final recommendation (39) is that the NDIA undergo 3 yearly external evaluation/ Audit by people with disability against the NDIS principles and objects in the NDIS Act.