

**Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape (Tune Review)**

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1. **Introduction**

I represent people who have Prader-Willi syndrome (PWS), their parents, carers and supporters. People with PWS have a lifelong need of significant support. They will have ongoing interactions with the NDIS. Therefore, we welcome the opportunity to contribute to this very important consultation,[[1]](#footnote-1) at the invitation of the Australian Department of Social Services.

I will provide a general explanation about PWS to improve your understanding, and respond to the specific issues and questions raised in the Paper, from the PWS perspective.

Prader-Willi syndrome (PWS) is a rare, life-threatening condition. It is a complex, multistage genetic disorder affecting multiple systems in the body[[2]](#footnote-2). It significantly impacts on behavior, learning, mental and physical health. Due to its complexity, there is a need for a multidisciplinary approach[[3]](#footnote-3) to support and management. It is important that the NDIA takes this into account when doing access assessments, comprehensive Plan development, and during Plan implementation. Effective service delivery also depends on a lot of indirect support hours for this group.

*‘BEST PRACTICE GUIDELINES FOR STANDARD OF CARE IN PWS’ have been published, for use internationally. More successful outcomes are achieved when service providers, educators and others adopt the specialist skills and techniques needed to support people with PWS*

People with PWS typically die young, due to complications associated with obesity. *However,* when PWS is managed properly, people with the condition can be expected to lead a more ordinary life, and live longer.

Families and carers of those with PWS have been found to suffer high levels of stress. The NDIS should not add a further administrative burden on the PWS community.

1. **Purpose**

The feedback provided in this submission refers to all topics of the NDIA service guarantee in the Discussion Paper, as they impact people with PWS.

1. **Response**
2. ***Principles***
3. *Which of the principles in the Discussion Paper do you think are important for the NDIA to adhere to, and why?*

PWSA agrees that Principles should be built into the NDIS Guarantee. PWSA generally agrees with the listed Principles themselves, but recommends improvements to the definitions of some. These are:

* Timely – The NDIS process will be easier to use, make timeframes clear, and be transparent about conditions under which it can extend its time commitments; The NDIA will be adequately resourced to deliver its services within its designated timeframes.
* Engaged – The NDIA should consult with the listed stakeholders, not just ‘engage’.
* Expert - NDIA staff have a high level of disability training and understand the impact particular disabilities have on people’s lives. They ~~understand~~ refer to expert advice about what supports are most effective for a person’s disability, and take a holistic view of how those impairments are interwoven, and impact *in combination*.

1. *In your experience with the NDIA, do you think they fulfilled the above principles? If not, how are they falling short?*

No, the NDIA has not applied those Principles effectively for people with PWS. In particular:

* Not timely: Appointments due to be scheduled by the NDIA have been scheduled late; this flows on to adverse consequences.
* The NDIA has not valued families: It has called meetings with the PWS Participant without the knowledge of the primary supporter, which is against best practice in PWS support and puts the Participant at risk.
* The NDIA has made it difficult for experts in PWS, often family members (who may also be professionals), to participate in upskilling support workers and mainstream organisations. The NDIA has done this by being too prescriptive about the qualifications of workers who can provide training. People with lived experience could otherwise realistically bring their expertise into the market place to improve choice for those with PWS.
* The NDIA has not valued Participants who need SDA, effectively forcing them to live in Group Homes, rather than in more independent specialist accommodation.
* The NDIA has not valued Participants. For example:
  + A single point of contact is named in Participants’ Plans. But members’ experience is that in some cases, despite attempts to make contact again over many months, the ‘single point’ has not responded. If that contact has changed role, the Participant has not been notified about their new ‘single point of contact’.
  + The NDIA has not set up an impartial website where Participants can learn more about provider performance, either from other Participants or the NDIA itself. The NDIA should be publishing findings of complaints about providers.
  + The Portal is not transparent in its information about Participants’ own information.
  + The method of quoting for, and negotiating on Supported Independent Living (SIL) services, within Specialist Disability Accommodation (SDA) is hidden from Participants. It is hidden by both the NDIA and the Service Provider. This prevents Participants from having the promised choice and control and negates the ability for the Participant’s nominee, or family support network, to monitor the provision of additional 1:1 support hours, where relevant.
* The NDIA has not been well connected; PWS Participants have been left without their approved supports whilst the NDIA argues with the provider about who will pay
* Decisions have not been made on merit: all adults with PWS need some kind of supported living arrangements, typically SDA. Despite evidence being provided, the NDIA through its circuitous administration, has made it extremely difficult for those Participants to implement the accommodation they need

1. *What other key principles are important for the NDIA to follow, that could be included in a Participant Service Guarantee?*

Dependability – An additional Principle: “The NDIA will demonstrate its commitment to Australians with disabilities by having a reliable and guaranteed source of funding, such that funds cannot be redirected to other policy areas.”

1. *One way to measure these principles is through a set of ‘Service Standards’. Some ideas for what these Service Standards could be are listed in Attachment A of the Discussion Paper. Do you think these Service Standards are fitting? Are there other standards you believe should be included?*

Considering that people with disabilities are in need of services from the start, a reasonable turnaround time by the NDIA would generally be 14 days. But there are some variations, in some new Standards. PWSA recommends:

* Timely Standards:
  + A draft of the Plan will be supplied to the Participant (and nominated Supporter) within 7 days of the Planning meeting
  + The Participant will provide any feedback on the draft Plan within 14 days of receiving the draft.
  + Plan will be approved within 7 days of the NDIA receiving the Participant’s feedback.
  + A Plan Amendment request will receive a decision with 21 days of receipt by the NDIA; this may cause a request for additional information, in which case the NDIA must respond within 7 days of receipt of the additional information
  + Where the Participant can prove that the NDIA has lost evidence already submitted, the NDIA will take action based on the original submission date, not the date when the evidence is found, or has been resubmitted
* ‘Engaged’ becomes ‘consults’ and the Standard becomes “The NDIA works with people with a disability to ensure their processes and operating procedures are designed to meet the needs of people with different abilities and needs, and can be understood by them. For example, some people with PWS can experience a sudden increase in support needs for challenging behaviours. As such, the NDIA’s rules and procedures must be able to respond quickly, to minimize harm and increase funding for the crisis period.
* Expert:
  + “NDIA staff will only interact with a Participant who has PWS, and/or consider their Plan after they have reviewed the NDIA training material about PWS.”
  + “The NDIA will ensure that it collaborates with PWSA to build the understanding of key NDIA staff about PWS; Key staff then act as an in-house resource to educate on the compounding impact of functional impairments in PWS”
* Connected - “The NDIA ensures that Participants do not experience service delays in circumstances where the interactions with other governments or mainstream services are not working well.”

1. *Do you have any ideas on how we can measure how well NDIA has delivered on each of the principles?*

Send surveys to Participants and their Nominees, where listed, for feedback. Participants and advocates must be consulted on the content of the surveys. The surveys need to be supplied by the NDIA to *all* its listed Participants *and* their Nominees. Ensure that results and analysis are divided into physical, cognitive, sensory and psychosocial impairment types, and split by results from the Participant or Nominee, so that results are not skewed. The survey needs to allow for anonymous completion. Ensure the methodology and granular results are available to the public.

1. ***NDIS access***
2. *What are some of the significant challenges faced by NDIS participants in the access process?*

Not enough understanding by Planners about the cumulative impact of multiple impairments.

Planners misinterpreting applicant’s answers, then filling in the online questionnaire for the applicant without explaining the options within the possible a question.

1. *The NDIS Act currently requires the NDIA to make a decision on an access request within 21 days from when the required evidence has been provided. How long do you think it should take for the NDIA to make an access decision?*

For applicants with genetic conditions, the decision should be made within 14 days.

1. *What do you think the NDIA could do to make it quicker or easier to access the NDIS?*

The NDIA makes access for adults with PWS unnecessarily onerous. PWS should be a ‘List A’ condition to streamline access which, is inevitable. Whilst Participants with PWS have variable functional impairment, they only differ in the degree of support need, which generally increases over time.

1. *Does the NDIA provide enough information to people when they apply for access to the NDIS? If not, what else could they provide that would be helpful?*

The NDIA could be:

* Proactive in the access process for people with PWS. A PWS diagnosis is made through genetic testing. At the time of results being delivered, the NDIA could arrange for parents to be informed about the existence of the NDIS
* More proactive in informing applicants about advocacy services

The NDIA must be ready to support potential Participants to make thorough applications if their condition is known to reduce their ability to interact with bureaucracies, Eg those with cognitive impairments.

1. *Is the NDIA being transparent and clear when they make decisions about people’s access to the NDIS? What could the NDIA do to be more open and clear in their decisions?*

At this time, only a few members of PWSA community have reported rejection experiences. These decisions have been reversed on appeal, however the need to appeal has causes unnecessary trauma for the family. PWS should be on List A.

There has also been a lack of transparency about reasons for funding levels.

***Creating the Plan***

1. *What are some of the significant challenges faced by NDIS participants in the planning process?*

People with PWS have impairments in executive brain function, along with other cognitive impairments. This makes it difficult for them to express their goals in ‘NDIS speak’. It also means it takes more time for these Participants to implement their Plans, even with significant support. The NDIA should not penalize Participants for a slow implementation by incorrectly concluding that unspent support funds equates to the absence of need.

Members have a low level of trust in the planning process, due to the variety of administrative mistakes that impact so many Participants and their families. Families of the Participant have to be vigilant to try to make sure that the process is working. It takes a lot of effort on top of an already stressful situation. When the NDIA fails to apply its own processes properly, the Participants and families have an added burden of monitoring and following up.

1. *Are there stages of the planning process that don’t work well? If so, how could they be better?*

Draft Plans must be supplied, with an opportunity for the Participant to provide corrections and feedback; The Plan should then be updated accordingly.

The ‘single point of contact’ must actually be contactable throughout the life of the Plan. Or the NDIA must proactively provide a new single point of contact if a Planner moves on. And that person must follow through on agreed actions, to make sure they happen. The contact should keep the Participant informed if there is a delay to completing the agreed actions. The Participant should not have to constantly follow up because they have not received information as expected.

1. *How long do you think the planning process should take? What can the NDIA do to make this quicker, remembering that they must have all the information they need to make a good decision?*

The NDIA should provide more information to mainstream provider about how to write reports that address questions the NDIA will have. That way, more useful information should be available at the beginning. At present, people with PWS are relying on advocacy services for report writing information, and they are under-resourced.

Getting reports is expensive. Some families cannot afford them. The NDIA should have a process to ensure Participants are facilitated to get reports early.

1. *Is the NDIA giving people enough, and the right type of information, to help them prepare for their planning meetings? If not, what else could they provide?*

Some people with PWS and their families have received training from an advocacy service to assist with planning meetings. It was very time consuming, but well received. Whilst planning booklets are available from the NDIS, some people find them daunting. Participants should be offered a phone or face-to-face service for an explanation and to assist with completion. More funding needs to be given to advocacy services. Where there are funding gaps for advocacy service, the NDIA should ensure funding, either from itself, or obtain a commitment from States and Territories to fund such services as they did pre-NDIS.

1. *Is the NDIA being responsive and transparent when making decisions in participants’ plans? If not, how could this be improved?*

No, it is not. Some improvements include:

* The Portal:
  + Needs to be transparent. It lists submitted documents, but does not allow the Participant to open those documents to be sure about what is in there. There should be a click through to the full documents. In addition, for payments that are Plan managed, the Portal does not let the Participant see which providers have been paid
  + Only shows the Plan manager’s name. This makes it more difficult for the Participant to build their knowledge and skills to better manage their Plan. It should allow the Participant to filter on all payments made to the actual payee, not just the intermediary. And for each provider, the item numbers paid, not just totals should be visible.
* Quotes for Supported Independent Living (SIL) services, within Specialist Disability Accommodation (SDA) is hidden from Participants. Service providers should be compelled to include Participants, and their Nominee/key support, in the design of the SIL quote, and reviewing the draft, if they wish.

1. *If you have been in the NDIS for more than one year, is it easier to make a plan now than when you first started? What has the NDIA improved? What still needs to improve?*

**Using and reviewing plans**

1. *What are some of the significant challenges faced by NDIS participants in using the supports in their plan?*

There is a serious lack of clarity for those living in SDA’s about which provider should be doing the day to day coordination of the Participant’s overall timetable. Even when a Support Coordinator is in place, they will not know the minutiae of changes to appointments, or a choice by the person with PWS to stay home that day rather than attend their usual community activities. SIL staff should be keeping all impacted stakeholders informed, so that the Plan budget can be used effectively. But this is not happening reliably.

1. *Is the NDIA giving people enough, and the right type of information, to help them use their plan? If not, what other information could the NDIA provide?*
2. *What other advice, resources or support could the NDIA provide to help participants to use their plan and find supports?*

There should be a rating system of service providers, for and by Participants, within the Participant Portal. This would build confidence in the sector, and encourage uptake. (It is not appropriate for the private sector to deliver that service, because their interest in monetizing such a website would discourage the level of transparency that Participants want and need.) Participants, being vulnerable consumers, need to be protected from poorly performing providers. A ratings site does not need to be public. The Providers would only see comments that were put up about their own organisations. But Participant’s and their nominees could see all ratings. The provider would have a right of reply to the Participant directly. If the Participant was satisfied with the response, they could remove their original comment, or qualify it with an update. Big data from such a ratings site is important; the NDIA could look at patterns and take its own action.

Participants want to have confidence in the integrity of the service providers available to choose from. The NDIA, in conjunction with the Quality and Safeguarding Commission, is not doing enough to keep scammers and fraudsters from joining the industry. Such businesses are experienced and sophisticated, with sharp practices. Whereas Participants with PWS and their supporters are novices, and already ‘snowed under’ by all the demands of living life with a disability. The NDIA should publish a list of ‘sharp practices’ that can occur in the sector, so that Participants can grow their knowledge and manage their Service Agreements more effectively. A fragmented and opaque market place benefits the scammers. A ratings site would enable Participants to be better informed, and would help build a competitive market place.

1. *What are some of the significant challenges faced by NDIS participants in having their plan reviewed (by planned or unplanned review)?*

* There is a lack of trust in the NDIA with Reviews. Members’ experience is that reviews have not been timely. It is unclear who is supposed to provide what reports. For example, the SIL provider has the most contact with a Participant. And yet their input to the review process holds less weight than a ‘professional’
* Members feel that the NDIA does not recognise the complexity of the needs of a Participant with PWS. As a result, the budget will be inadequate, and not properly address:
  + All the administration (non-contact) hours of service are also needed. For example coordinating appointments across 12 health domains and 44 existing or potential health conditions caused by the genetics of the disability.[[4]](#footnote-4)
  + The additional training needed by staff that support people with PWS. Because PWS is rare, service providers cannot have appropriately trained staff immediately available, so PWS-specific training will take time and resources, needing budget
  + If there is a behavioral outburst, there follows some hours of administration, including reporting and remediation (ie indirect support)
  + That a PWS Participant’s circumstances can change suddenly, or their goals may change during the middle of a Plan; It is extremely onerous to in those circumstances to get through a review in a timely manner

1. *What can the NDIA do to make this process easier or more effective?*

Acknowledge the baseline needs of a person with PWS, and guarantee appropriate funding. This is particularly important for adults who have reached a more predictable lifestyle, and could then seek funding for goals over and above the maintenance of their day-to-day life.

Even with a successful Plan review, at times, people with PWS have been turned away from service providers who say “we do not offer services to meet your needs”. The NDIA can make sure that there are providers of last resort available to people with PWS, where restrictive practices are available and in place to save their lives. This would ensure people with PWS have choice and control when using their Plan budgets.

1. *How long do you think plan reviews should take?*

* A Plan Amendment request should receive a decision with 21 days of receipt by the NDIA; this may cause a request for additional information, in which case the NDIA must respond within 7 days of receipt of the additional information
* A review requested because of disagreement with a decision should be completed within 21 days.

***Appealing a decision***

1. *What are some of the significant challenges faced by NDIS participants when they seek a review of an NDIA decision?*

It is:

* Stressful trying to follow a process in which most of the PWSA members have no experience
* Time consuming when families or Nominees are already very busy supporting the person with PWS.

1. *Are there other issues or challenges you have identified with the internal and external review process?*

Not reported by members at this time.

1. *How could the NDIA improve the decision review process?*

Make the rationale for the decision transparent, including specific details. This will ensure the Participant has the best chance of understanding why, building their knowledge, and addressing gaps in information provided, where applicable.

Ensure that individual, personal guidance is available for the process, through independent providers.

1. *How long do you think reviews of decisions should take?*

No longer than 21 days.

***Removing red tape***

1. *Do you think there are parts of the NDIS Act and the Rules that are not working or make things harder for people interacting with the NDIS?*

At times the diagrams of processes are too high level. Some people want more detail so they know what to expect. This will help them engage with the process more effectively. High level diagrams should have ‘click through’ options at each step, to give Participants more detail, in context.

1. *What changes could be made to the legislation (if any) to:*
   1. *Improve the way participants and providers interact with the Scheme?*

Refer to the above responses.

* 1. *Improve the access request process?*

Move PWS onto List A.

* 1. *Improve the participant planning and assessment process?*

Drafts of Plans must be provided at each stage, with opportunity for feedback enshrined.

* 1. *Better define ‘reasonable and necessary’ supports?*

Where cases have gone to the AAT, but settled beforehand, the outcomes should be de-identified and made public. Currently the conclusions about what was found to be reasonable and necessary are not transparent.

Many more examples of reasonable and necessary scenarios should be provided on the website, although details not needed in the Legislation.

* 1. *Improve the plan review process?*

Manage Participant expectations better. Make sure the single point of contact is available for discussion, before the Participant starts an unplanned review process.

It is very important that the NDIA educate the health and allied health sectors about how to write reports that address the questions the NDIA will want to know. A template could be added to a Schedule in the Legislation to standardize reports and manage expectations.

* 1. *Improve the internal merit review process?*

It is unclear to PWSA what this is.

* 1. *Improve the way other government services interact with the Scheme?*

Much more work is needed with State and Territory Governments who are ‘stepping back’ far too quickly from supporting people with disabilities. There are no accommodation providers of last resort transparently available to Participants. Mental Health services are disappearing. Advocacy services like the Office of the Public Advocate and Community Visitor program are badly needed and need ongoing commitment from their State and Territory Governments in the interests of the disabled.

***Plan amendments***

1. *What are the significant challenges faced by NDIS participants in changing their plan?*

Sometimes the request for a change is only about one part of the budget, for a specific support need. But the Participant has an upheaval of their whole Plan, including changes to other parts of their budget, not requested. This has resulted in instances where funding has been taken out of the plan, such as the removal (pro-rata) of unspent funds that the Participant may have been ‘banking’ for a planned support need toward the end of the Plan period. This should never happen. It adds further confusion and mistrust into the process.

Participants should be informed about the potential consequences of their review request before they formally submit it, so they know what to expect. For example, if a ‘light touch’ review only moves funding around within an existing budget, the Participant should be fully informed that there will be no extra budget, and another part of their Plan will be compromised by the ‘budget shuffle’.

At times reviews are requested because the Participant does not understand the deficiencies in the existing information supplied. They do not understand what extra information is required. The NDIA needs to make that quite explicit at the time of rejecting a Participant’s request.

1. *How do you think a ‘plan amendment’ could improve the experience for participants? Are there ways in which this would make things harder or more complicated for people?*

An amendment process could be easier. But the NDIA must make the definition of a Plan amendment very clear. And the NDIA must not interfere with other parts of the budget that were not part of the Amendment request. There must also be a right of appeal.

If extra reports are needed, then the NDIA should provide extra budget for those. The Participant should not have to spend their budget that was supplied for approved services.

1. *How long should people have to provide evidence that they need the changes they are requesting in a plan amendment?*

As long as they need. If the Participant needs the extra support, they will be motivated to supply the information as soon as possible. It is unpredictable as to how long it will take to get that specialist’s appointment, and then to receive the report(s). So, fear of missing a deadline should not be driven by NDIA arbitrary deadlines. The NDIA should make it clear that the Participant cannot expect an amendment decision until 14 days after the new information is supplied, whenever that may be.

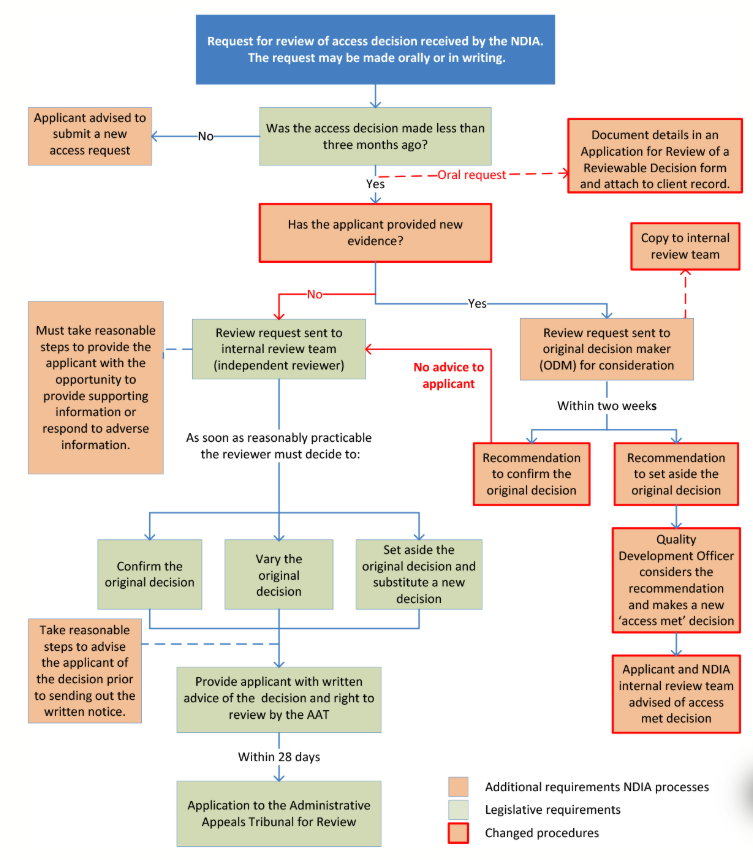
1. *Are there other situations during the planning cycle where a quicker and easier way to make changes may be necessary?*

Obvious errors should be fixed over the phone. For example, if a name is wrong, or a submitted report is not appearing on the Portal.

In many situations, a call to the NDIS help desk should be escalated to the single point of contact for a discussion. A clarification with a person who knows the case will be the quickest way to identify the magnitude of the error, and the best path to a solution. The single point of contact should respond within 48 hours.

1. *How else could the NDIA improve the process for making changes to a plan?*

Provide clearer diagrams about the process *and* possible outcomes at each step, such as the one in the ANAO report, sample below.[[5]](#footnote-5)



1. **Conclusion**

The PWSA is very committed to supporting children and adults with PWS. Generally, members of PWSA have found that the Plans finally reached have been meeting the needs of the Participants. But the process has been onerous and frightening. Members see more work ahead of them, to continue navigating the NDIS. ‘Plain sailing’ is not in sight.

Also, there are many other PWS families who have not been in contact with PWSA and may be experiencing access and review hurdles.

Therefore, the ideas in this submission are proposed with the goal of making the NDIS a better experience for existing and new Participants with PWS.

If you would like to know more, PWSA has created, and plans to continue developing a variety of resources for NDIA and support workers. These can be found on our website at <http://www.pws.org.au/ndia-worker-lac-advice/>

Thank you for the opportunity to contribute. I would be happy to discuss these ideas in more detail if that would be useful.

James O’Brien.

1. The Consultation Paper was available from the web page <https://engage.dss.gov.au/review-of-the-ndis-act-and-the-new-ndis-participant-service-guarantee/ndis-act-review-and-ndis-participant-service-guarantee-discussion-paper/> [↑](#footnote-ref-1)
2. Vanderbilt PWS Health watch table Vanderbilt Kennedy Centre <http://iddtoolkit.vkcsites.org/physical-health/health-watch-tables-2/prader-willi-syndrome/> [↑](#footnote-ref-2)
3. A multidisciplinary approach to the clinical management of Prader–Willi syndrome <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6418440/> [↑](#footnote-ref-3)
4. Vanderbilt PWS Health watch table Vanderbilt Kennedy Centre <http://iddtoolkit.vkcsites.org/physical-health/health-watch-tables-2/prader-willi-syndrome/> [↑](#footnote-ref-4)
5. Australian National Audit Office: Decision-making Controls for Access to NDIS Report 2017-18 <https://www.anao.gov.au/work/performance-audit/decision-making-controls-sustainability-ndis> [↑](#footnote-ref-5)