

Response to consultation on Planning Policy for Personalised Budgets and Plan Flexibility

Autism Aspergers Advocacy Australia, known as A4, offers the following response to the NDIA's Consultation Paper on Planning Policy for Personalised Budgets and Plan Flexibility.

While the paper says, "we want to hear from participants, their families and carers, and the disability sector on how we can deliver a more consistent and fairer approach to planning and personalised participant budgets", A4's experience is that the NDIA consistently ignores and rejects our input, suggestions and advice. A4 knows that the NDIA's Participant Service Charter is a sham. However, we provide this brief response in the hope that our view might make a difference for once.

The NDIA has already decided how it will change budgeting and planning. The Paper describes participants reporting problems to the Tune Review, but the NDIA's response creates more problems than it solves.

- People are already reporting confusion and frustration with the so-called "Independent Assessment" process.
- Contracted assessments, the so-called "Independent Assessment", are not transparent and delay progress with the NDIS for participants who already have independent assessments for clinicians that they paid previously for their diagnoses.
- Little or nothing in the changes better informs new participants and people with newly recognized disability.
- In some cases, the new system may be marginally easier to navigate, but when something goes wrong the proposed changes appear substantially (and intentionally) more difficult to navigate.
- The proposed changes clearly reduce recognition of expertise and respect for participants and their families
- The proposed changes are regarded as demonstrating that the NDIA and its staff do not understand disability and constantly ignore its complexity at both the individual and systemic levels. The NDIA is simply unable to listen to people with disability and to representative organisations.

A4 acknowledges that the process that the NDIA used during its initial roll-out should be reviewed and can be substantially improved.

The NDIS is better for most participants than the previous system of disability supports. However, the NDIS still falls well short of its goals and its prospects. There is considerable room for improvement.

In A4's view, the proposed changes will not lead to improvements.

New NDIS participants from now on will be mostly people who are new to living with disability. They deserve a different approach. It makes sense to engage with them multiple times during their initial planning process ... as appears to be described at Step 1 and Step 4 of Figure 1. Some people who

are starting their lives with disability might benefit from a more progressive introduction to support planning than just two initial meetings – greater flexibility may be needed.

Ideally, the NDIA would have a credible co-design process with the disability community, especially the DROs who have knowledge, expertise and insights into changes likely to be improvements.

A4 regard the so-called “Independent Assessment” process as a massive step backwards. It will reduce the NDIS to a national version of the Independent Support Packages (ISPs) that the NDIS was meant to replace.

The Paper says

The current process for building plan budgets, based on a need to assess whether every individual support is reasonable and necessary, has resulted in inconsistent decision-making and a high volume of reviews. Currently, participants with similar levels of functional capacity and environments may have very different levels of NDIS funding. Significantly, evidence exists that the current approach to assessing a person’s functional capacity is leading to inconsistent and inequitable plan budgeting decisions.

The NDIA has been told repeatedly that its “current approach to assessing a person’s functional capacity” is flawed. For example, the NDIA was told repeatedly that its use of the PEDI-CAT for autistic children is proven to be inappropriate, but the NDIA continues to use the PEDI-CAT to assess autistic children. The NDIA could not even allow intake officers to note that a PEDI-CAT assessment did not appear to indicate a child’s functional capacity.

The NDIA seems unable to understand that when people have different goals, even if they have similar “functional capacity”, their goals may be “reasonable and necessary” so their supports will vary (which the NDIA chooses to call “inconsistency”). Basically, having the NDIS attempt to address people’s varied goals leads to varied funding. Varied funding means the NDIS is probably delivering mostly on its goals.

The NDIA reports extremely high levels of participant satisfaction despite the Agency alleging problems with “inconsistent and inequitable plan budgeting decisions”.

The Paper says

Under the new policy, we want to deliver fair plan budgets to all NDIS participants. We will do this by using consistently gathered information from a holistic independent assessment to inform a participant’s reasonable and necessary level of funding. This means plan budgets will be clearly aligned with a participant’s level of functional capacity, including the impact of their environment.

The danger with this approach is that consistent gathering of information limits what information is gathered. The approach does not gather all the information relating to “reasonable and necessary” supports and their funding. This statement admits that the NDIA’s proposed process is “clearly aligned with a participant’s level of functional capacity”. This “new policy” changes the objects of the NDIS, to limit planning to *current* functional capacity, takes no account of the early intervention aspects of the NDIS Act 2013 that are meant to address future functional capacity, or of goals that can change a person’s environment and future functional capacity.

In its section 3.1, the Paper lists some Principles. A4 seriously doubts these principles guide the NDIA’s changes. It would be more convincing were the NDIA to deliver on measurement and reporting of its achievement of these principles.

Section 3.7.1 about plan variation could be clearer about how to handle situations where part or most of a plan can be approved but some items may warrant further consideration and subsequent funding. It should be possible to get an initial plan allowing someone to get started or to continue their existing support, while further consideration is given to additional or replacement supports.

Using the term “check-in” to replace “review” is inappropriate. Just say that the NDIA wants to change the review process.

As an organisation, A4 welcomes and accepts the explanation in this Paper of why so-called “Independent assessment results will not be directly reviewable by the AAT”. Many A4 members are as yet unaware of or may not understand the reasons. A4 understands that while a so-called “Independent Assessment” cannot be subject to review, the consequent planning outcome can still be subject of internal and AAT review.

The NDIA could be substantially clearer about the options for a planning and decision review where a so-called “Independent Assessment” presents a different description of functional capacity or support needs from the described needs in a relevant clinician’s report.

A4 is aware that the NDIS already has a fully dysfunctional complaints process – of course we expect that the so-called “Independent Assessment” process would be subject to that system.

1. Consultation questions

1. How should a participant’s plan be set out so it’s easier to understand? How can we make it easy for participants to understand how their funding can be spent?

In most instances, having participant plans focus on the actual supports the NDIS intends to fund, rather than on the dollars would improve everything. It would encourage people to focus more on using services to deliver support and achieve goals. People might be a bit more interested in quality rather than quantity ... which could improve outcomes (usually resulting in long-term saving).

Cost negotiations might best be done between the NDIA and service providers, and reduce the involvement of participants in cost issues.

Participants should be focused mostly on whether or not they get the services and supports they need, not on detailed accounting for dollars.

2. How can we support participants to prepare for a planning meeting? What might be needed to support participant decision-making?

Participants need more understanding of the planning and budgeting process and of their options. Previously, many new participants had experience of disability supports. Hopefully from now on, new participants are mostly new to the whole disability support arena. New NDIS participants are from a new cohort of applicants.

New participants may need more progressive access to information and to the whole disability support challenge. The process may need to be spread out to give them more time to better understand what is happening for them and what challenges and possibilities exist.

3. Which supports should always be in the fixed budget? What principles should apply in determining when supports should be included in the fixed budget?

Clearly this varies between disabilities. Perhaps the starting point should be typical goals for individuals with a diagnosis type or similar “functional capacities”.

Asking this question shows that functional capacity does not determine/predict essential supports.

If existing research does not answer this question, then a co-design process with DROs and others could provide a starting point.

In relation to autistic children, evidence-based early intervention should be available as an option.

Basing supports on individual goals remains an essential principle.

4. How can we assure participants that their plan budgets are at the right level? (e.g. panels of the Independent Advisory Council that meet every six-months to review learnings and suggest improvements)

Participants know best if their plan budgets are at the right level. The challenge is whether participants know what to do about it when it is not right. Increasing AAT reviews suggest that participants are becoming increasingly aware of what to do when funding is not at the right level.

The IAC has demonstrated that it has little or no real understanding of ASD, the most common distinct disability for NDIS participants.

5. What new tools and resources should we provide to support people using their plan and new plan flexibilities?

The sector needs massively improved support coordination.

The NDIS should start using plain language as a tool – it uses a lot of jargon. For example, it does not fund “horse riding” but it may fund “equine therapy”, it doesn’t fund “respite” but it may provide parents with a break while a support worker takes their child out for “community access” (even if there is no actual contact with any community). You miss out on services if you don’t know the NDIS jargon.

6. What do we need to consider for children aged 7 and above in the new planning process?

The NDIS needs to consider that autistic children are autistic 24/7, not just while they are at school.

Best-practice early intervention for ASD does not stop at age 7 years, or when a child starts school.

Autistic children who are excluded from school need disability supports during school hours.

Autistic children whose parents work often need more support than other children while their parents try to work.

7. What ideas do you have for how people can use their plan more innovatively?

The NDIS needs to cease its “NDIS says ‘No’” responses.

We have many ideas, but the main/over-arching one is that the NDIA should respect participants and their families.

8. How best to handle the timing of the release of funds into plans and rollover of unused funds?

Currently, with annual release, people are using about 80% of their funds on average. If planning periods are long, it may be that most people can manage an annual funds release quite adequately.

If there is a reason to change, maybe another period can be negotiated.

9. How should check-ins be undertaken? Under what circumstances is a check-in needed? Who should be involved in a check-in?

Please don't change the term to "check-in"; just call it a review but expand the types of review as needed.

The review process can be improved.

10. How often should we check-in with participants in different circumstances?

By mutual agreement, or when some change or exceptional circumstance deserves a review.

11. How can the NDIS ensure positive relationships between participants and planners?

The big issue here is the NDIA's chronic disrespect for participants. While NDIA staff expect people with disability are *all* completely dishonest rorters, out to risk their financial futures by claiming a few extra dollars, the relationship between participants and NDIA staff will remain toxic.

12. How can we best support participants to transition to this new planning model?

Existing participants transitioned to the current model relatively smoothly. Participants are not the problem. The main problem is the often-unexplained policies and the inability/failure of NDIA staff to implement them consistently.

Good luck!

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