



Action for More Independence & Dignity in Accommodation

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Advocacy, Self Advocacy, Rights, Accessibility, & Community Living for People with a Disability

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To the NDIA
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Response to NDIS Consultation paper: Planning Policy for Personalised Budgets and Plan Flexibility

AMIDA is a government funded advocacy organisation and we are part of AMIDA's NDIS appeals support service. We work with NDIS participants and potential participants in relation to a wide range of NDIS issues. We are responding to the NDIS *Consultation paper: Planning Policy for Personalised Budgets and Plan Flexibility* (hereafter referred to as "the consultation paper") released in November 2020.

We are concerned that the changes outlined throughout the consultation paper will not address the current challenges outlined at 2.1 of the consultation paper. We are also concerned that the NDIA is using the consultation paper, and the other papers released at the same time, to consult on the process of implementing pre-determined changes rather than consulting on the substance of the changes. This is not in keeping with the Participant Service Charter.

Our opinions are primarily informed from our work over several years as advocates in our roles at AMIDA. We believe we have a comprehensive understanding of the way the NDIS currently works and are well placed to comment on the changes outlined in the consultation paper. We have read the consultation paper, and attended workshops and seminars conducted by the NDIA and other advocacy organisations. In our response, we make some general comments and address some of the current challenges before answering the specific questions asked in the consultation paper. Suggestions as to how the NDIA can improve the NDIS are made throughout.

General Comments and Current Challenges

In 2019-2020 we provided service to the parents of two primary school aged children. The children and their families were unknown to each other. Both children were the same gender, born within 3 months of each other and both were the eldest of a sibship of 3. Both children were living with a very severe form of a relatively rare developmental disorder. Both children did an additional year at kindergarten to try to get them more prepared for mainstream school. Both children participated in the same types of therapy. Both children's parents lived with them and their siblings in the family home. Both their mothers were not in the paid workforce citing the extra responsibilities of caring

for their eldest child as the sole reason for this. Both children were participants in a longitudinal research trial into their disorder conducted by the Murdoch Children's Research Institute. Both children saw the same highly regarded specialist. Both children's parents provided very similar assessment reports and recommendations to the NDIA. The similarities between the two children were truly striking. The most obvious difference between the children was the suburb they lived. One child lived in one of the highest socio-economic area of Victoria whilst the other lived in a suburb generally considered as much further down the socio-economic scale. The other difference was their NDIS plans. The child who lived in the higher socio-economic area had a plan budget that was more than double the plan budget of the child who lived in the lower socio-economic area. There was no discernible reason for this.

We share this story to demonstrate that we are very aware of inconsistency within the NDIS. We welcome attempts by the NDIA to address such inconsistency as it can lead to great unfairness. However, we do not believe that the changes outlined in the consultation paper will address the inconsistency on show in our example. In our example the reports and recommendations provided to the NDIA to inform each child's plan were remarkably similar. The children's environmental factors, defined in the consultation paper as the physical, social and attitudinal environment in which people live and conduct their lives, were extraordinarily similar. Except for the suburb they lived in. The inconsistency here was a result of the NDIA's own planners, and delegates, making different decisions when presented with very similar information.

Nor do we believe that the changes outlined in the consultation paper adequately address the list of frustrations found by the Tune Review and listed at 2.1 of the consultation paper. We think it valuable to comment on how the changes outlined in the consultation paper may impact these frustrations.

The NDIS was confusing and frustrating.

Some of the changes outlined in the consultation paper will go a long way to making the NDIS simpler to understand. In particular, the removal of many different categories under core, capacity building and capital budgets is a welcome change. The concept of fixed and flexible budgets will be easier for many participants to understand. However, the introduction of mandatory independent assessments makes the application process and the planning process longer and more protracted which is likely to lead to more confusion and frustration. Making people jump through more, at times completely unnecessary and potentially harmful, hoops is not likely to reduce confusion and frustration.

They were frustrated about delays and lack of transparency around how the NDIA made decisions.

The NDIA is to be commended for the improvements to decision making times. It is not that long ago that a request for a plan review under s100 would routinely take 8-11 months to complete. This was a dreadful experience for participants, and we welcome the improvements the NDIA have made in this area. However, we have serious concerns that the changes outlined in the consultation paper will do little to improve transparency around how the NDIA make decisions. The consultation paper describes, at 3.3, how the "personalised budget approach will replace the current practice of using Typical Support Packages (TSP) as a reference along with participant information gathered in planning to develop a participant budget. Unlike the TSP, the personalised budget will ensure a stronger link between a participant's level of functional capacity, including their environmental and personal context, and their level of funding." We have been unable to find any publicly available information about the NDIA's use of TSPs. We have been to dozens of planning meetings and have asked on several occasions about TSPs and have been variously told that, TSPs "do not exist", TSPs "are not used" and TSPs "are not used anymore". Without further information about what the TSPs are and exactly how and when they are used it is simply not possible to comment on whether the

new personalised budget approach is a better, a preferred or even a different approach. The consultation paper is lacking in detail around exactly how the independent assessment will be used to determine the draft budget. This only serves to increase the frustration caused by lack of transparency around how the NDIA make decisions.

They wanted to have more support to become informed and effective consumers.

The changes outlined in the consultation papers could go some way to helping participants become informed and effective consumers. However, much more information about how exactly this will be done is required to ensure that participants are truly supported. The consultation paper states, at 3.3, that “detailed guidance, in line with the Applied Principles and Tables of Support, will be provided to prevent participants paying or being charged for services where they should not be”. It is not enough for the NDIA to provide a participant with copies of the Applied Principles and Tables of Support and then leave them to deal with their providers. More should be done at a much higher level than the individual participant to ensure providers and service systems are complying with the principles and tables. We note that the consultation paper is silent on the role that support coordination can play here. There has been no information provided by the NDIA about the results of the Support Coordination consultation conducted in September 2020. Support to help a participant become more effective consumers may be more appropriately done by a Support Coordinator than by the NDIA.

They felt the NDIS was too complex and difficult to navigate.

Some of the changes outlined in the consultation paper will go some way to improving this. As mentioned above the removal of the many different categories of support will help. The proposed check in process has the potential to be enormously valuable. However, there is not enough detail around who at the NDIA will be present at the check in and how the check in process interacts with the role of a planner or a LAC. It will be important that the NDIA representative at the check in is the same person that did the last check in. Ideally this person should be the planner who attended the planning meeting. We have had dozens of participants tell us that it is difficult to get in contact with their planner or LAC when they have a query or question. It is not uncommon for NDIA staff to refuse to give participants their email address, phone numbers or even last names. There is no point implementing a new system if it will just replicate the same problems. The check in system could help alleviate the complexity and difficulty navigating the system only if the person conducting the check in already knows the participant and their circumstances well enough to ensure that it can be a valuable interaction.

They felt they were not recognised as the experts in their disability.

The changes outlined in the consultation paper around increasing flexibility may help alleviate some of this frustration by allowing participants to manage their funding more flexibly to suit their individual circumstances. However, the introduction of mandatory independent assessments as the starting point for determining an overall level of reasonable and necessary funding is likely to further increase this frustration.

They felt the NDIA staff did not understand the nature of their disability or appreciate the challenges they encountered in everyday life.

It is difficult to see how the changes outlined in the consultation paper will address this frustration. The check in process could potentially be way that NDIA staff improve their understanding of a participant’s disability and the challenges they face, but only if it is done well. There is not enough information provided in the consultation paper to suggest this will be the case.

Response to questions in the consultation paper

1. How should a participant's plan be set out so it's easier to understand?

NDIS plans are easier to understand when you have seen several them. They are also easier to understand when you have someone available to explain how they are set out. We have had positive feedback from participants who attended LAC run plan implementation sessions where several participants gather in a room to go through their plans. This allows participants to see the individualised nature of their own plan and to ask specific questions about their plan.

How can we make it easy for participants to understand how their funding can be spent?

Provide participants with the option of a plan implementation meeting, either individual, group, or virtual, for them to ask questions about how their funding can be spent. These should ideally be conducted by the planner who conducted the planning meeting.

2. How can we support participants to prepare for a planning meeting?

We are often asked by participants what they need to do before a planning meeting and how they can be best prepared. Unfortunately, our answer must be vague. We have attended planning meetings where the planner had not read any information about the participant. We have attended planning meetings where the planner had comprehensively read everything, including reports that are many years old. We have attended planning meetings where the planner knew nothing about what supports the participant had used in the previous plan period. We have attended planning meetings where the planner had a clear breakdown of where funds had been spent and had suggestions for other supports the participant might like to explore. The planning meetings are driven by the planner and their individual approach. The only way to prepare a participant for them is to make sure the participant is across as much of the detail as possible and that they be prepared for a number of potential scenarios. There is nothing in the consultation paper that makes us think that our advice to participants will change.

What might be needed to support participant decision-making?

This will depend on the participant. NDIA staff should first and foremost be aware of how the relevant state-based guardianship and administration laws may impact a participant's decision making. Generally, a participant will need to know:

- When a decision needs to be made,
- What the potential options are,
- What the main implications of each option are,
- How to find out more information about the options,
- When they need to decide,
- Whether and how easily they can change their decision.

3. Which supports should always be in the fixed budget?

We are not convinced that any supports should *always* be in the fixed budget. The consultation paper gives a range of examples of supports that could be fixed including employment supports, provider travel and SDA, however we are concerned that requiring certain supports to always be fixed directly contradicts a participants right to choice and control. There will be some participants who would prefer to have all their funds fixed to allow them to have clear boundaries and limits as to what they can spend their funds on.

What principles should apply in determining when supports should be included in the fixed budget?

The changes outlined in the consultation report regarding whether funds will be fixed or flexible remind us of the experience of participants in deciding whether their plans will be self or NDIA managed. In our experience this decision is often the subject of a value judgement from NDIA staff. We have had a recent experience where an NDIA staff member refused to allow a participant to self manage their funds “because we know they will go straight out and buy a Fitbit and we just can’t allow that”. The consultation paper states, at 3.5, that the “reason for including funds in the fixed budget will align to the NDIS Act, Rules and Operational Guidelines and be clearly explained to the participant”. We hope that this will be the case but, in our experience of the way a participant ‘chooses’ the management of their plan, the alignment and the explanation are often lacking.

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)

This will be a difficult thing to do. We have been a part of several conversations since the consultation paper was released where this question was discussed. Almost every time a participant smiled wryly and responded, “well, that’s simple, just by actually putting the budgets at the right level.” Generally, we have noted that participants trust their therapists more than they trust the NDIA. So, if an occupational therapist advises a participant that they need to be seen fortnightly and the NDIA disagree and say monthly is the right level almost every time the participant will believe their therapist over the NDIA. The question is really centred around how much participants trust the NDIA.

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

There should be a broad range of tools and resources to support people. Participants should be asked what types of tools and resources they want and the NDIA should follow up on the individual requests.

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

That one or both of their parents are usually the one making decisions for them. That children may be capable of making their own decisions. That the guidelines around what constitutes parental responsibility are often unclear and are inconsistently applied.

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

In our experience the major barrier in a participant using their plan more innovatively is the NDIA saying no. We have had a number of participants who have come up with ideas about how they could use their plan innovatively but when they check the idea with a planner they are told they are not allowed. Some of our s100 review requests contain innovative ideas for using NDIS funds. They are refused and during the subsequent AAT case conference process the NDIA’s position changes and they are allowed. If the NDIA simply said yes more often, and earlier, it would encourage innovative plan use.

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

Ask each participant what will work best for them and implement it. The timings can be reviewed at check ins to ensure participants remain happy with the arrangement. There is likely

to be a wide range of preference for how the release of funds are timed. The participant's choice should be paramount.

9. How should check ins be undertaken?

As described above, we believe the check in process has the potential to be enormously valuable. However, it also has the potential to further exacerbate the frustrations participants have with the NDIA if they are not undertaken well. The consultation paper describes a process where the frequency of check ins will be "discussed at the participant's planning meeting and be decided by a delegate". The participant should agree with the decision. How they are done; face to face, over the phone, email or virtually should also be agreed. It should be a priority for the NDIA that the same staff attend a check in to ensure they are familiar with the participant and their circumstances and to avoid the participant having to tell their story multiple times.

Under what circumstances is a check in needed?

The consultation paper outlines a range of circumstances where a check may be needed. These are all likely to be reasonable. Of crucial importance is that the participant can initiate a check in and be able to make contact with the relevant person easily.

Who should be involved in a check-in?

- The participant,
- The planner,
- Anyone the participant wants with them.

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

This is a very broad question. It will be different for each participant's individual circumstances.

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

There are several ways the NDIA could improve relationships between participants and planners.

- Consistency of planners. In our experience the planner is not usually the same one from the previous planning meeting. This makes the prospect of developing a relationship redundant. The NDIA could improve this by understanding why planners do not stay in their positions and take steps to address the reasons.
- Removing planner anonymity. Participants are required to supply the planner with an abundance of information about themselves, often in quite intimate detail. It does little to ensure a positive relationship when the planner then refuses to give the participant their contact details or their surname.
- Empowering the planner. Participants know that the planner isn't the one making the final decision. The decision is made by the delegate, who the participant usually has no opportunity to meet, speak to, ask questions of, or further explain their circumstances to. Empowering the planner to make decisions that they can justify and explain directly to the participant would go a long way to improving relationships between participants and planners.
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12. How can we best support participants to transition to this new planning model?

Listen to the feedback you get from this consultation. Conduct some well run trials of the new planning model. Ensure that this really is the best planning model before any commitment or change is made.

Conclusion

There are some positive changes outlined in the consultation paper. Increased plan flexibility and the check in process in particular have the potential to make the NDIS much easier to navigate and will potentially go some way to alleviate some of the more common frustrations of participants. However, there is little in the consultation paper to suggest that the changes outlined will deliver a more consistent, and therefore fairer NDIS. In line with the Participant Service Charter, the NDIA need to provide more detailed information about the current practice of using TSPs and more detailed information about precisely how the results of an independent assessment will be the starting point for determining a participant's personalised budget. Without this further information there is no way to make a good comparison between current practice and proposed changes.

Yours sincerely,

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