



Summer Foundation Submission to the Personalised Budgets and Plan Flexibility Consultation

February 2021

Introduction

The Summer Foundation supports all efforts to improve the flexibility of budgets and to increase choice and control for people with disabilities. Therefore, we welcome policy and improvements that will lead to simpler, fairer and more flexible plans.

We are however concerned that personalised budgets alongside independent assessments may be used to reduce funding packages for people who have high and complex needs. A recent quarterly report says “[t]he change in the way assessments are undertaken is needed to implement a Scheme that, from a participant’s perspective, is more consistent, fairer, and lower cost...” (page 9).

“I also can’t help but be concerned about [independent] assessments being brought in every 5 years for people already part of the NDIS. My first concern is that if this is done within the context of cost-cutting, it could become a disincentive for people to improve their skills and general functioning. Secondly, when we are talking about people who have their housing dependent on funding from the NDIS, the potential for major disruption (or fear of disruption) could be a major issue.”

– Helen, participant

Additionally, we are concerned that the participant’s housing and support goals, needs and preferences will not be considered in the development of personalised budgets. For example, participants who want to, and for whom it is in their best interests to, live alone or with loved ones will be forced into group living situations.

The Summer Foundation is concerned that proposed changes are indicative of a planning process that takes control away from the participants. While flexibility within budgets will be beneficial for participants, it may create new challenges especially in the initial planning process where plans and budgets are developed without consideration of the individual needs and preferences. For participants to be in control of their lives and of their NDIS plans, personalised budgets need to reflect the person’s goals and their needs and preferences.

It is essential that any changes to planning, personalised budgets and budget life cycle are designed to empower participants. Capacity building is needed to support a participant to effectively engage in the planning process, particularly where they are determining a budget for a longer term.

Currently, in many circumstances, participants are reporting that they have minimal engagement or influence in the planning decisions or budget allocation. A more inclusive process is needed, as are supports that enable a participant to effectively engage and make informed and empowered decisions about their lives.

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?

Participants must have access to information in their preferred format such as simple and easy English. This should include both audio and visual examples and case studies of other (de-identified or example) plans. These examples must demonstrate clear and simple methods of how funding may be spent.

Plans need clear descriptions about what the fixed funding covers, such as Specialist Disability Accommodation (SDA), home mods, Assistive Technology (AT), etc, with planners and Local Area Coordinators (LAC) explaining clearly how the rest of the participant's flexible budget will fit into their needs and preferences.

A participant must have the opportunity to work with a planner to shape their plan in a collaborative and informative environment. Plans need to be descriptive (by the participant) to guide the allocation of budget and services, post planning meeting. A participant must be confident that their plan provides access to the reasonable and necessary supports they require to live an ordinary life, over the lifespan of the plan.

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

Prior to the planning meeting, it is essential that participants receive a full and easy English summary report and explanation of the results and findings of the Independent Assessment (IA) along with their draft budget. This summary should be accompanied by an explanation of how these findings have been interpreted for the purposes of establishing what are reasonable and necessary supports.

A participant should be empowered and be able to have supporters in the meeting to ensure they are able to provide additional evidence and advocate for the right funding levels. They must be able to articulate the funding allocation they would like in order to achieve their goals. Participants may need to talk to family, friends, their support coordinator or to an advocate for guidance and support through the planning process. It is important that this information is provided to the participant at least a week before the planning meeting to allow time for the information to be considered and understood. The NDIA should never make a decision ahead of the meeting.

The Summer Foundation is concerned that many participants are not being supported to make decisions and fully participate in the planning and review process. Supporting participants to make informed decisions is of critical importance for a successful NDIS. Participants must be supported to explore housing and support options and to have their housing needs and preferences respected and upheld. A preference to live alone, or any

other goal, should be reflected in a participant's NDIS plan. A crucial element of addressing this is support coordination, as well as adequate information and resources to allow participants to fully participate in planning.

While it may be important not to standardise plans, there needs to be some consistency in the funding that is approved so participants and support coordinators know what their options are.

"I would like to have podiatry included in my plan, and my support coordinator tells me that it is often approved for people in wheelchairs. However, my planner would not approve it when we requested it and was quite adamant about it."

– Helen, participant

There are many issues around planning processes, including a lack of emphasis on participant input and contribution. Likewise, there is often insufficient funding of support coordination and delays in approval of Supported Independent Living (SIL), SDA and AT. This forces people with disabilities to enter or remain in residential aged care (RAC), be stuck in hospital or in other inappropriate housing.

To assist participants to make decisions around their housing and support, adequate support coordination and Specialist Support Coordination needs to be made available to more participants and expanded to cover secondary consultation for support coordinators, encompassing comprehensive housing search and mentoring.

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?

Generally speaking, only SDA, AT and home modifications will likely be fixed while other supports must be flexible. The Summer Foundation advocates for participants to have maximum choice and control over their NDIS supports in line with the *NDIS Act 2013* and the United Nations Convention on the Rights of Persons with Disabilities. We understand however that some participants may not have the capacity to manage their budget. In such circumstances, the NDIS should ensure the appropriate supports are in place including plan management support and support coordination.

"Planners, assessors and everyone involved needs to approach their work seeing possibility, not just problems. If the aspirations and goals of people with disability are taken out at the early stages – i.e. in the development of the personal budget – it seems that the foundation of the process/eventual plan could be in danger."

– Helen, participant

These supports are important safeguards that help to build the person's capacity to appropriately manage their budget. For some participants these safeguards may not be sufficient and it may be appropriate to include some essential supports in the fixed budget category such as funding for SDA, support with daily activities and some therapy supports. As well, certain needs should trigger specific supports, such as the need for SDA meaning that a participant should automatically be funded for support coordination to guide them through the process and support transition.

However, this decision to restrict flexibility should only be made after a fair and thorough assessment and receiving advice from people in the person's life who know them well.

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 6 months to review learnings and suggest improvements)

It is important that plan budgets are sufficient to achieve the goals of the participant.

There is a risk that planners/LACs will continue with their "it's out of our hands" mantra, which will be even more detrimental now that there are fewer avenues for appeal.

To address funding insufficiencies, the Summer Foundation recommends the following:

- Support coordination funding needs to be sufficient to enable people to implement their plans and achieve their goals. Participants with high and complex needs are not receiving funding for support coordination at a level that meets their needs. Significantly, those who require Specialist Support Coordination are either not receiving it or are not receiving it at the appropriate level.
- Too often, participants' housing needs and preferences are not being reflected in their NDIS budgets by funding them for shared living when their goal is to live alone. If someone has a reasonable goal to live alone, their budgets should be sufficient to make this possible.
- Pricing needs to be sufficient to enable people with high and complex needs to find suitable providers. As an example, [current MTA](#) pricing is too low for people with complex and high support needs due to their specific needs, which may include additional features in a house and/or living alone.
- Funding needs to be included for reasonable and necessary AT and home modifications. Too often, there is insufficient funding for these items or there are long delays in assessment and approval processes. These delays can result in a person being forced into aged care or stuck in hospital.

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

Participants must have planning tools that enable them to visualise the process and brainstorm how they will use their plan to achieve their goals. Resources should be available to highlight how plans can be used flexibly to achieve outcomes, incorporating the experience of other participants around how they have used their plans. The NDIS must ensure that providers understand the changes and can communicate these changes to participants.

Capacity building for participants must be made available to assist them in understanding, influencing, shaping and managing their plans. This is critical for the success of the NDIS and needs to commence, or be available, prior to the first plan. To do this well, a review, 'trial and test' period of the first plan should be implemented to allow the participant to explore the NDIS service availability, develop an understanding of what they need and build their capability to negotiate with the planner to set a sufficient plan for the next period.

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

It is important to consider the rapport building between child supporters/drivers and the assessor, and how those dynamics affect the participant. Supports must be in place to consider various environments in which children may be most comfortable.

These planning processes should operate with the child's normal structure and routine in order to lessen disruption and discomfort.

The planning process must identify and incorporate meaningful tasks for children, allowing them to pursue their own goals. This work must address the motivation, emotional needs and barriers present in the child.

It is essential the planning process allows for parents to understand all options that are available for their child and how they can utilise funding to best support their child. It is critical support coordination is funded and enables capacity building for the family to be able to define goals that best support the child to grow with their individual needs front of mind and flexible funding to support this.

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

There are a number of ways that participants can be supported to use their plan more innovatively.

Firstly, it is important that more participants are supported and encouraged to self- manage and "plan manage" their plans. Plan management is an important stepping-stone towards self-management, so it is important the option of plan management is maintained and there is capacity building available for those who wish to move towards self-management.

Secondly, to encourage innovation, the government should place no limitations on what participants purchase and who they purchase it from, apart from requiring funding to be

spent in accordance with the law, and that the support is in line with the person's goals as outlined in their plan.

Thirdly, it is important to make sure participants understand the flexibility available in their plan. Support coordinators have an important role to play in assisting a participant to understand the flexibility of their plan as well as how to self-manage their funding and be innovative in how they purchase supports. For example, they may need assistance to understand their obligations when directly employing support workers and how to engage a bookkeeper.

Fourthly, the NDA should promote and showcase innovative uses of funding packages so people can learn from the examples of others.

Finally, governments should continue to fund disabled persons organisations to undertake capacity building work that provides peer support and training related to self-management and exercising choice and control under the NDIS.

"It is really frustrating that no matter how much the NDIS plans are supposed to be structured for flexibility, it is still really difficult to move funds from one area to another. For example, using funds from core for professional services such as physio OT."

– Helen, participant

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

Some participants need funding to make large purchases at some points in time while needing less funding at other points. It is important any new rules around the release of funds and the rollover of funds recognise this. Releasing funding in small portions may be problematic for some people.

"I have found that often I use funds at different points of the year rather than consistently. If I had to justify underspends and negotiate rollover of funds, it would just create another layer of tension and bureaucracy."

– Helen, participant

The ability to rollover funds across years is essential. Many people, especially those with a newly acquired disability, take a long time to start using their NDIS supports depending on their current environment, needs and access to supports.

Similarly, people may save funds for times where extra supports will be needed. The government should not be taking back funding that has not been spent because there are often very good reasons for this. Allowing people to rollover funds also encourages better spending habits and allows a person to plan for an ordinary life. The rollover of funding will enable participants to chase value rather than spending funding out of fear that it will be taken away.

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

Check-ins must be individualised and conducted to suit each participant. There must be clarity about the purpose of the check-in and what can and cannot be determined or achieved from it. The participant should be informed in advance to prepare and set up the support they need to participate. A check-in should be an opportunity for a participant to advise their planner about what they need, if anything has changed and how their goals are progressing. This should be a positive goal-orientated meeting that supports future planning.

Participants must be in control of when a check-in occurs. A check-in may be needed in a change of circumstance, to support someone at a known interval or for other reasons such as needing increased funding to cover supports. This provides reassurance that if things are not working, they do not need to wait 12 months for a review to change things.

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

Check-ins should occur every 6-12 months or as life changes for participants. This process would happen rather than an annual plan review. Participants should be able to arrange a check-in prior to planning meetings to ensure that they are prepared for that planning session.

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

Productive and meaningful relationships between participants and planners must be built of mutual respect, where participants are supported to feel they are fully contributing to and participating within the planning process. Planners must make the process and their decisions clear and simple to understand and navigate. Planners and participants should have a clear line of communication moving forward in the participant's preferred manner. A general phoneline or email address is insufficient. Participants should be able to contact their planner when they need to.

The NDIA should empower planners to be able to have authentic and useful conversations with participants. Planners must have up-to-date knowledge around how to use plans innovatively and flexibly.

Planners must be skilled, committed to supporting the participants and kept up to date with new policies, price guides and decisions. Far too often there are instances of different planners providing different access or answers based on their interpretation or understanding of the current environment. The NDIA must ensure planners are well versed in the most up-to-date and current policies and that they implement consistently.

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

The new planning model process should have a pilot stage to ascertain the range of needs and barriers present during the transition. Participants must know what to expect and how to address these concerns. The NDIA must give participants opportunities to share their experiences with other participants and share ideas about how to use their funding flexibly and innovatively.

This pilot should ideally take place with both new and existing participants in order to capture both experiences. Both groups must contain statistically significant numbers of people across a spectrum of disabilities that show a range of experiences. The findings and results of this pilot must be transparent and accessible to the public. Without such a pilot, it would be inappropriate for the NDIA to begin this new approach, particularly where it is intended to be partnered with independent assessments in 2021.

There is a significant piece of work to be done in preparation for this transition with planners, LACs, participants and the broader sector. Support coordinators need upskilling on the new flexible approaches to be used within plans to best support participants establish, manage and utilise their plans - this could efficiently be done through Summer Foundation's [UpSkill program](#).