

Consultation Paper: Planning Policy for Personalised Budgets and Plan Flexibility

Overview

The Client Consultative Committee (CCC) of CPL Choice Passion Life was started in 1993 in recognition that clients wanted a platform to advocate issues. The CCC provides engagement forums for clients to be able to speak about their issues and get involved in organisational decision making and planning.

With a 30-year history, the CCC representatives continue to provide feedback to CPL executives and senior management on a number of internal and external issues including things like transport, housing, health, staff training, rostering, support needs and NDIS matters of concern.

Ms Jennifer Johnston, current Acting Chair of the CCC, is submitting client feedback that has been captured with regard to the NDIS request for consultation paper – planning policy for personalised budgets and plan flexibility.

CCC and CPL worked collaboratively to gather opinions from participants and parents relating to this consultation paper and with a focus for feedback on the questions of;

- *As an existing participant of the NDIS what impact do you think the proposed changes of receiving your funding monthly or quarterly will have on your daily life?*
- *As an existing participant of the NDIS what impact do you think the proposed changes of receiving your funding monthly or quarterly will have on the way you manage your budget?*

Participant and parent feedback was sought across Queensland and received from the following locations;

- Jenny, Gold Coast (participant)
- Nigel, Brisbane (participant)
- Andy, Ipswich (participant)
- Ben, North Queensland (participant)
- Brendon, Logan (participant)
- Sruti, Brisbane (participant)
- Chris, Wide Bay region (participant and parent of 4 participants)
- Juno, Gold Coast (parent of a participant)
- Wendy, Gold Coast (parent of a participant)
- Jenn, Brisbane (parent of a participant)
- Peter, Brisbane (parent of a participant)
- Effie, Caboolture (parent of a participant)

- Anonymous male, Ipswich (parent of a participant)
- Dainie, Darling Downs (parent of a participant)
- Merv, Brisbane (parent of a participant)
- Julie, Gold Coast (parent of a participant)
- Susan, Caboolture (parent of a participant)
- Yvonne, Central Queensland (parent of a participant)
- Diane, Sunshine Coast (parent of a participant)
- Melinda, Gold Coast (parent of a participant)
- Trudy, Sunshine Coast (parent of a participant)

Question Responses

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 NDIS plans need to explain in plain English what can be purchased from each category. For example:

- Assistance with Social, Economic and Community Participation - you can use this funding to pay for a support worker to assist you to access the community.
- Improved Daily Living- you can use this funding to purchase therapy support to build your skills or have assessments completed for things like equipment. Some examples of the types of therapy that can be purchased include Speech Therapy, Occupational Therapy, Physiotherapy, Psychology, Dietician, Exercise Physiology and Social Work.
- Improved Life Choices- This funding is used to pay for a plan manager to assist you with managing your plan funding and pay invoices for your supports purchased under your plan. Having a plan manager allows you to buy supports from registered and non-registered NDIS providers in the categories that are plan managed.

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

It's critical the participant and/or nominee receive the draft plan in plenty of time for the NDIS plan review meeting, and in their preferred format. Many elderly nominees do not use email (or access the Portal), so need hard copies mailed out, and many younger nominees (e.g. those who work full-time) are overwhelmed by the number of emails they get and are very time poor. It would be easy for them to overlook such an email. It would be useful for the NDIA to phone the decision maker and ensure they have seen and understand the draft plan.

Extra time needs to be allowed if the Office of the Public Guardian is involved, due to the time it can take to reach them/liaise with them.

If someone has support coordination in their plan the Planner should seek the participants permission to share the draft plan and budget with the Support Coordinator. The Support Coordinator can support the participant and/or nominee to understand budget, particularly if there are changes with new terminology, rules and categories. They can also assist them to prepare for their plan review meeting.

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?

SDA, Home Modifications, Assistive technology individual items, SIL, nursing support, plan management should be included in the fixed budget. This money should be available at the beginning of the plan not released monthly or quarterly increments.

For children therapy (Improved Daily Living) should be a fixed budget item as evidence suggests that early therapy reduces the impact of disability.

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)

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

Response:

A participant from Brisbane said: "I would also require extra support to manage a flexible budget - I'm used to having my therapy funds and support worker funds separate and would need to learn how to manage if these were all flexible. I am concerned that if I use more than my monthly allowance, I would be responsible for the bill - My supports are generally stable week to week, but occasionally I fluctuate slightly within the month and require some flexibility. I might not recognise that I have overspent as I am used to working within an annual budget."

Response:

A parent of a participant on the Gold Coast said "I already rely on a Support Coordinator to assist to track the budget so that we don't overspend during the year. We will need more support to work out how we can manage the budget to meet my daughters needs during different times of the year."

It would be useful for the Participant and their Support Coordinator to be able to see on the portal the processing stage of all transactions. It would also be important to see the date of

the services that are being claimed. This will allow them to have a more accurate sense of the funds available and whether funds need to be set aside as providers are delayed in submitting invoices/ claims.

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

Many families of children with a disability are exhausted as they meet the usual needs of children but also their disability specific needs. Often children with significant disabilities and their families do not have the same options as other children their age such as having play dates and sleepovers with peers and staying with extended family. These activities provide a natural respite. Due to this families may prioritise core support type activities over therapy supports that build their capacity. Core support funding should be available to provide assistance to children with a disability and their families but funding for therapy may need to be fixed.

Children's needs change rapidly, and more regular check ins would be required. Planners need to have the ability to assist with submitting fast tracked plan review applications to increase funding:

- If medical intervention is anticipated, (for example, operations relating to disability – ileostomy, spinal, gastrostomy, amputation, etc.)
- At puberty (behavioural changes, AT needs, managing continence/menstruation)
- When children move from primary to high school or finish high school or become unable to attend school (additional support, employment, SLES, socialisation)

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

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

Response:

“The monthly or quarterly limits on allocation does not allow flexibility for unplanned or extra supports needed say over a month and not perhaps needed in another month - give flexibility in one hand, take it away with the other and how will this work with more expensive items/services? What about the SIL - how does this work with more support required during public holidays etc where Day services are not available. If the assessor has no background on the participant how can they possibly evaluate how much funding is required each month or quarter. You can't just divide the amount by 12 or 4 and say you will use the same amount each period. What about time out for ill health e.g. and not being able to participate in services for up to a month or on the hand when more support services are needed. Who chooses whether monthly or quarterly and what is the criteria used to ascertain this? I realise you aren't allowed more than the monthly allocation but what if funding is not all used in one period can it be carried over to the next month or quarter or have you lost it?”

Response:

“This will put a lot of pressure on me to run and keep to a budget over the short term. This goes against choice and control. There would be no problem if she did the same thing every day that fitted in to a monthly budget. My daughter won’t be able to choose to have a holiday or take part in an activity that requires a higher level of support, because of fears of running out in the short term. I will have to rethink taking care of my health - and any surgeries that are needed, simply because they may not fit in to the time of the Plan when we will have a saved allocation of funds to ensure that my daughter is supported when I can’t be there. It has already been published that the majority of Participants underspend on their annual budget, this cannot be sold as being in the interest of the individual. It seems to be a way to control a small proportion of people - this seems to be overkill and certainly will have a negative impact on choice and control.”

Response:

“Monthly and quarterly payments do not provide any flexibility in real life routines and life changes.”

Response:

A parent with 4 children with disabilities aged 10-17yrs said in regard to the proposed monthly or quarterly release of funds: “That's b*****t! Some months you may need more funding for Allied Health Therapies (more intense therapies may be required). The NDIS are taking away choice and control on how and when supports are accessed.”

Response:

A parent of a young person with a disability, said in relation to the proposed monthly or quarterly release of funds “This would impact us hugely. My wife and I do the bulk of or sons personal care supports and use his daily activities funding in short bursts when we go away on caravan holidays which our son is not interested in attending. Often, we will use a large percentage of his budget within a 4-6 week period, and then not use any daily activities budget for weeks on end. Our son’s community supports remain consistent throughout the year, but his total budget is definitely not delivered in even quarterly chunks. As stated above, it would be impossible for us to manage our budget the way we have been if we only had access to a quarter of his yearly budget at a time. The way our son has chosen to have his supports delivered has enabled us to maintain a high level of informal support (as we are able to get support into the house when we go away and our son doesn't want to join us in the caravan) and has enabled our son to not have to access respite facilities - which he simply finds too traumatic.

Response:

A participant at Ipswich expressed concern about what would happen when unpredictable things happen: "I am prone to pressure injuries. If I develop a significant pressure area this leads to a high expenditure on consumables and nursing support. If funding is released monthly or quarterly, I may not have enough funding to afford to pay for this. Also, if I have a major equipment repair this may lead to me having to forgo care in order to be able to afford this. This could jeopardise my general health and well being in terms of positioning and pressure injury management."

Response:

A parent of child with a disability said: "This will have a significant impact on my sons access to needed services. Currently there are capacity issues within our community to access therapy. As soon as my son came off the waitlist for Occupational Therapy we were engaging in intensive support. This has now tapered off and we attend less frequently yet still routinely. My son is still on the waitlist for Speech Therapy. Once capacity opens for him, he will access the service intensely. There are months where I require large amounts of funding to meet my son's needs, and other months where I do not. This is the same for consumables. His funding utilization is impacted by his needs at the time, as well as provider capacity."

Response:

A participant who is soon to move into SDA accommodation will need many Occupation Therapy hours initially to assist with the home automation of his unit. He said "Having the funding released monthly or quarterly would not allow me the flexibility to get things done when I need them done."

The vast majority of participants and nominees that provided this feedback were very concerned about funding being released in monthly or quarterly intervals and felt this would greatly limit their flexibility and choice and control. The NDIS is very slow in its ability to respond to participant/nominee requests currently. It does not have the suppleness to respond to requests for the early release of funding to meet the real life needs of participants.

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

This should be determined by the participant. Some may welcome the opportunity to come in for 30min chat every 3 months. Others may prefer to communicate by phone, email, text. This should be determined by the participant/ nominee. The Planner should seek permission from the participant/ nominee -to contact the Support Coordinator (if they are funded for this) as part of the "check in" process.

E.g. Nominees who may not have engaged well with the NDIS rollout may be inclined to state that “everything is going well”, not realising (or sometimes remembering) that their budgets are not sufficient to meet the person’s needs. The participant/nominee should also be able to identify other stakeholders they wish to be involved in the check in process.

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

As often as participant nominates. If Planners are concerned that a participant is at risk or particularly vulnerable, they may encourage more frequent check ins. They should also ask permission to check in with other significant stakeholders, especially if they are unable to contact the participant/ nominee.

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

Feedback from participants and nominees on the proposed changes has impacted negatively on people’s perception of the NDIS. Comments such as the following were gathered from participants and their families:

Response:

A parent from Ipswich with multiple children with disabilities said: “Changing the rules so often, to suit the NDIA and not participants and family. They said they were not going to do stuff like this. I think going down this track will put more pressure on parents and family relationships.”

Response:

A parent of an adult child with a disability said “My husband and I have retired and feel that these changes are going to impact on us and increase the stress and reduce our son's choices. It no longer seems that we have any control as the decisions in how and when we do things is being made by the NDIA not us!”

Response:

A father of an adult participant; “There is a general view that the NDIA has become an unresponsive bureaucracy, very autocratic, and a law unto themselves. The consequence of this is the NDIA is now being viewed by many as being unpredictable and untrustworthy. The NDIA proposals fly directly in the face of previous government commentary in support of the scheme.”

The importance of having a consistent person at the NDIS that they can contact directly was identified as something that would be helpful:

Response:

A participant from the Gold Coast said: “For me, it comes down to there not being enough resources to manage the NDIS Plans. It would be good to have one point of contact, build a relationship with that person who knows you and your situation, and

it be an ongoing partnership. And more frequent communication, and even face to face. At the moment there is no clear line of communication with the NDIS - I have had my LAC change so many times and not be told - and when I try and call them I can never get through. This would go a long way to helping people understand the NDIS, feel supported in the process, to know their plans, and how to use them more effectively.”

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

Some participants and nominees will benefit from having Support Coordinators to support them to navigate new processes. The NDIS should ensure Support Coordinators are well trained and informed of any new processes so they can offer effective support.

The CCC would welcome further opportunity to engage with NDIA in similar consultation processes.

Thank you for your consideration.

Jennifer Johnston

Acting Chair

Client Consultative Committee (CPL - Choice Passion Life)

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