



AUTISM QUEENSLAND RESPONSE TO THE NDIS CONSULTATION PAPER: PLANNING POLICY FOR PERSONALISED BUDGETS AND PLAN FLEXIBILITY

Autism Queensland welcomes the opportunity to provide its feedback on the above Consultation Paper. Our organisation recognizes and appreciates the investigation and work that has gone into preparing this Consultation Paper.

Autism Queensland has some comments, questions, concerns and suggestions about aspects of the information in the Consultation Paper that are not covered in the specific questions posed by the NDIS at the end of the Paper. We will present this feedback first, then provide our replies to those Consultation Questions.

Autism Queensland feedback on issues not covered in the Consultation Questions

1. Under Section 3.1 of this paper, which is entitled “Principles”, it is stated:

The principles of this policy are that people with disability experience a planning process which upholds the intent of the NDIS Act and associated international conventions. This includes a commitment that the new process will:

- a) *provide personalised budgets which balance individual circumstances and the sustainability of the NDIS*

This statement is presented in a manner that indicates that the Act supports modifying the funding for a person with disability even if the supports identified are Reasonable and Necessary, if providing such supports could be taken to impact on the sustainability of the NDIS. The implicit message is apparent in many aspects of the Consultation Papers, that the responsibility for the financial sustainability of the NDIS rest solely on people with disability being prepared to accept less than what is optimal for their outcomes, so that the Scheme can remain viable.

We consider this to be a misrepresentation of the Objects of the NDIS Act. Whilst there is reference within the Act to “the need to ensure the financial sustainability of the National Disability Insurance Scheme”, this is very clearly not stated as being achieved through limiting the funding available to a participant who has clearly been shown to need a certain amount of funding. Ensuring the financial sustainability of the NDIS, as expressed in the Act, means that the Agency and the Government are obliged to find ways to fund the Scheme so that it can provide the amount of funding needed to genuinely ensure people with disability ‘have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development’ (General Principle 1 under Objects and Principles within the NDIS Act). We also consider General Principle 8 to be particularly relevant to the discussions and proposals currently being covered in the three Consultation Papers: ‘People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.’

2. Step 2 of the proposed planning process states “An NDIS delegate considers a budget informed by the outcomes of the independent assessment and identifies any additional supports required”:
 - a. As referenced a number of times in the Response Submission and Autism Queensland’s Response to the Independent Assessment Consultation Paper, what methodology is being used to interpret functional capacity assessment results as dollar values?

- b. How can the delegate identify any additional supports required prior to meeting with the participant?
3. The consultation paper includes a 'planning case study', but there is no reference to any pilot programs that have been implemented around this change – have there been any pilots? If so, why have we not heard about them and where is the information from these? If not, how can there be a case study?
4. How will this change impact clients with supported independent living (SIL) funding?

Autism Queensland response to the Consultation Questions

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

- Given the significant changes that are being proposed to participants' plans, Autism Queensland presume that the Plan document itself will undergo quite extreme changes. Without seeing what those are likely to be, it is difficult for us to make comment. The following points are based on our and our clients' experience with current plans.
- Current plans contain large sections that repeat the same pre-prepared information. This does not help the participant to feel that the plan has been individualised. It also makes the plan confusing to read. For example, in the current goal section, where information about short-, medium- and long-term goals is stated, there is a sentence for each goal, then a table with 2 columns, one headed "How I will achieve this goal" and "How I will be supported". The information for many participants in each column is the same for each goal, regardless of if it is short-, medium- or long-term. Autism Queensland suggests that there is a separate page that simply lists the goals, which the participant can then present to and work with providers on how to address them. Autism Queensland also strongly suggests that Partners and delegates receive in-depth training on how to write SMART (Specific, Measurable, Achievable, Realistic, Time-limited) goals, otherwise how can there be any judgement on whether the participant's NDIS goals have been realised?
- The inclusion of significant information about the management of the funding just adds bulk and more words to the Plan. Autism Queensland suggests that this is covered extensively prior to and during the Plan meeting, with relevant information materials provided at that time so that the participant's plan simply states what funding management method/s have been chosen by the participant.
- The use of first person throughout is demeaning, clunky, uncomfortable and illogical. Many of the comments are instructions or information from the NDIA to the participant e.g. "I can refer to Booklet 3 to help me understand my NDIS plan..." Normal and respectful language for such comments would be "You can refer..."
- Use the same terminology in hard copy and online versions of plans.

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

- The person that the participant/carer is meeting with (partner, planner, delegate) should be making suggestions about appropriate supports if these have not been raised by the participant/carer, *especially* for first plans. Not the actual providers, unless this is relevant (e.g., only one provider delivers this support, or the participant's own requirements mean that only one or a certain number of providers are going to be appropriate), but a type of service that the NDIS representative should have the expertise to recognise would be an important support but of which the participant/carer may be unaware.

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

- Within the current process, some participants are unaware of any support available to them from the partners in preparing for planning meeting. Therefore, Autism Queensland would suggest that clear communication is required from the start of the process to ensure participants are as informed as possible of the assistance partners or other NDIS representatives can offer. Autism Queensland suggests that there is a standard number of interactions with each participant in the lead-up to the planning meeting to share information about what to expect, what details they need to have already decided, etc.
- Within the current process, other participants have found that the information they can access about getting ready for their planning meeting has not been helpful. From their reports, we ascertain this is largely because the partners are communicating using NDIS jargon and also because they are presenting as being concerned first and foremost with adherence to NDIS bureaucratic parameters. Autism Queensland recognises that all NDIS representatives must comply with NDIS requirements. However, participants would find it more helpful if the NDIS representative was focussed first on the participant and what would be most useful to the participant (including, as mentioned above, making suggestions of other supports, either NDIS-funded or not, that the participant/carer may not have considered), followed by the discussion of how this could be accessed – what the NDIS funding could be used for and what would not be able to be funded through the NDIS).
- Understanding of best practice by participants/carers has been raised in other NDIS Consultation Papers. Autism Queensland suggests that all NDIS staff who are likely to be in the position of communicating with participants/carers about their plans and/or supports, should have significant and ongoing professional development in this area. We have experienced widely varying demonstrations of this understanding amongst NDIS staff and, given the importance of participants'/carer's understanding of this concept, along with the key role that NDIS staff play in conveying this message to participants/carers, this should be addressed.
- NDIS representatives need to be particularly focussed on assisting participants/carers if the amount in the draft plan is less than they had expected or planned on.

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

- Without more significant knowledge of how this new process would look and work, the below suggestions are preliminary. This question, along with many others, should be asked again, and the process be flexible enough to take on further changes as information becomes available.
- High cost supports.
- SIL – however, there has been no information provided on how any of these changes will be implemented for participants who receive funding for SIL.

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)?

- Firstly, define 'right level'. Right level for whom?
- Autism Queensland cannot emphasise this next point strongly enough – information is required to inform participants/carers, providers and professionals how functional capacity assessment results are being translated into a dollar amount. Evidence to show how this will occur and its validity is paramount if there is to be any success in gaining trust and 'buy-in' from participants that their plan budgets are being

appropriately determined. There is significant participant/carer cynicism and suspicion already entrenched around the apparent primary focus of the NDIS being to keep costs down, in particular to find all means possible to keep participants' funding budgets as low as possible. If this is not the case, the NDIS needs to show how a budget that has been pre-determined by a functional capacity assessment (a methodology that does not have any pre-existing information or evidence to support it) has actually led to a budget amount that enables the participant to access all the supports necessary to achieve all their goals. The fact that there is a problem already recognised by the NDIS of participants/carers not seeing their funding budgets as adequate is a clear indicator of the seriousness of this issue. Participants should not need 'assurance' that they are receiving sufficient funding if the process leading to that point has been informative and individualised.

- An acknowledgement that the 'right level' of budget will change along with needs and that the system should have the flexibility and capacity to change with the changing support needs of the participant.

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

- Increased recognition and support to providers who are frequently put in the position of assisting participants or potential participants to understand and navigate the NDIS system. These changes will mean many alterations to our working arrangements with existing clients, which in turn represents significant extra time needed to explain those changes, as well as the additional admin load of making changes to templates, information papers, Service Agreements and more.

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

- Improved interaction between the Agency and the education sector.
- Facilitation of truly informed choice through NDIS representatives actively suggesting relevant and appropriate supports if these are not mentioned by the child's parent/carer.
- Making the transition process from the Early Childhood Approach to the general Scheme as straightforward as possible, with the EC Partners and LACs working collaboratively for each child that this applies to.
- Having a dedicated pathway for school-age children that recognises the unique needs and intersection with relevant systems and mainstream services for this cohort.
- Recognise that school aged children have a limited time in which they can access supports during the school week. Schools have all but banned NDIS therapists/staff from entering schools to support students in their everyday environment during school hours. There are limited hours left to access other groups and supports. The current therapy pricing is not viable for organisations to pay therapy staff to work on weekends. There is a shortage of therapists in the NDIS workforce – they are not going to work on weekends for the same amount of money as they can earn in a Mon-Fri 9-5 role. The Price Guide needs to cost weekend/out of standard hours therapy supports to accommodate penalty rates.

What ideas do you have for how people can use their plans more innovatively?

- As referenced above, a common belief by participants/carers is that the goal is to keep participants' NDIS funding budgets as low as possible, so there is a cynical reaction to the word 'innovatively' – is this another way of saying 'cheaply'?

- Being innovative is hard work and expectations should not be placed on participants/carers to be innovative when they are likely to be stressed and exhausted. Their budget should be seen by them as appropriate for meeting their needs without requiring significant effort to find ways to expand the funding necessary through being 'innovative'.
- This comes back to the understanding, knowledge and skill of anyone in a position to provide information to participants regarding support options available to meet their goals. Unfortunately, many NDIS Planners promote traditional clinic based individual supports ahead of more 'innovative' options, often due to their limited understanding of how different looking supports might assist in achieving goals.
- The prescriptiveness of the Price Guide limits provision of innovative supports. We have many 'innovative' models that are progressive and consistent with best practice and current research, yet these are incredibly challenging to cost according to the Price Guide and to be financially viable to deliver. Effectively, if the Price Guide hasn't pre-empted a model of service provision, it cannot be costed viably and completely stifles innovative practice. It's the tail wagging the dog.
- Innovative may not be cheaper in the short term but the gains may exceed traditional models of support, making it more cost effective in the longer term. By talking about using plans more innovatively, is there acknowledgement of this?
- Stepping out of the medical model when deciding which qualifications are recognised as eligible to provide services e.g. teachers with special education / inclusive education qualifications and experience. By restricting utilisation of the teaching workforce to under 7's, workforce capability and service provision capacity is lost.

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

- This matter generated several comments and caused concern for a number of parents and participants involved in information sessions that were held recently. Many were very fearful of a vastly increased administrative load on themselves if, for example, funds were being released on a monthly basis. It would seem that considerably more consultation with participants and carers is required to ensure that this proposed process is genuinely helpful for them rather than another burden.
- Similarly, further information is required on how flexible the amounts would be. For example, across a 12-month period, a participant may either intend, or otherwise end up, using large amounts during one funding release period and smaller amounts at other times. How will the amount per release be determined? Whilst there is reference to the rollover of unused funds, there is no information on what would happen if the amount the person wanted to spend during such a period was more than what had been released to them. If this is going to require the participant/carer to request a change to that funding released, this will create the same problems as are currently experienced with participants having insufficient funds in Capacity-building or Core and needing it to be moved.
- If the participant's fund budget is to be for a 12-month period, is it possible simply to have all of the funds accessible and give the choice and control to the participant on the timing of when they will use them? Breaking it down to shorter time periods seems to be giving an unnecessary amount of oversight and control to the Agency, in a way that is potentially demeaning to participants and carers.
- Given the significant challenge accessing many services and the length of wait lists, isn't it to be expected that some participants may have extended periods not utilising funds while they are on waiting lists, then start utilising and need access to their funding? Regarding therapy supports, service provision often doesn't happen in a steady fashion, utilising the same amount each week or month – if this is the therapy supports model being accessed and indeed promoted, then this is in contradiction of best practice

guidelines. Therapy supports should ebb and flow according to the goals and support needs of the client as they live their lives.

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

- They should be kept as informal and useful as possible; able to take place through whatever means works best for the participant at the time (face-to-face, email, phone, online).
- We would suggest that there is a basic set time period, such as 6 weeks after the commencement of the Plan, then 6-monthly, where the NDIS representative would contact the participant to see how things are going, but if the participant indicates all is well and they are not requiring any assistance, nothing further takes place; then along with that, there is the understanding that the participant can contact the NDIS representative at any time to request a catch-up/check-in.
- The check-in should involve the participant and/or the participant's representative, the NDIS representative and anybody else that the participant/participant's representative would like to involve.

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

- Change the focus or the wording of interactions to build participants' confidence that planners simply want what is best for the participant.
- Minimise the emphasis on the need to keep costs down; the NDIA's need to manage the cost of the NDIS is an issue for the NDIA, the government and taxpayers to address, it should not be placed on the shoulders of individual participants.
- Planners should make proactive, informed suggestions of supports that could be helpful; the experiences that Autism Queensland has had with participants where this has not occurred have boiled down to 2 concerning reasons:
 - The planner's focus on keeping costs down has been interpreted that if the participant doesn't ask for it, it won't be included, even when the support would be reasonable and necessary and would make significant improvements to the participant's outcomes.
 - The planner has been unaware of supports available, or the relevance of particular supports to the participant in question.

Both scenarios are unacceptable and do not support informed choice.

- Planners should speak knowledgeably about supports available, both funded and mainstream.
- Planners should acknowledge when they don't know information, go and do the necessary research and report back to the participant.
- Planners need to speak plainly, avoiding NDIS jargon – it can be difficult to recognise just how much jargon any of us working in specialised settings do use without frequent reminders, training and self-awareness.
- Put time into explaining plan management options and checking participant's thoughts and preferences.
- Listening and finding ways for the person to either access a support they want that can't be funded through the NDIS or for the person to understand why that support is not advisable.
- Ensure consistency across individual staff within the organisation (NDIS or a partner organisation) – there have been just too many examples of completely different information being given by different staff members.

- Demand knowledge and consistent application of NDIA-determined processes – there have been too many examples of Partners acting in ways / providing information that is in conflict with what is available on the NDIS website / in operational guidelines.

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

- The NDIA should communicate directly with each participant, through a variety of methods – letter, email, phone, radio, television, using simple, non-jargon language, keeping it brief and offering opportunities for the participant to receive more information if they would like it.

Submitted: 23 February 2021