Submission to the NDIA “ Support for Decision Making”

10 September 2021

Dear NDIA

Thank you for the opportunity to make a submission. (Please keep my name anonymous though content may be shared)

Participants with autism make up one third of the NDIS participants. Are autistic people without intellectual disability being included in the category of those with ‘cognitive impairment’? I do not think this has been made clear in the document. Please make some reference to participants with autism so they and their families know if and how you are including them in this discussion.

I am concerned about the NDIA’s action of reducing numbers of nominees. Is the NDIA’s reasoning that directly reducing nominee numbers will result in increased or improved participant decision making capacity? Is the NDIA putting forward a thesis that nominees are adversely affecting the participants capacity to make decisions? And if there are other reasons for this policy, people with disability and their families have a right to know.

I would like to see provided and published research and evidence that reducing the nominee numbers will result in increased decision making capacity for nominees; and if there is a lack of evidence, then it would be prudent to have a pilot project like a clinical research project done in conjunction with a university and advocacy organisation.

If the NDIA decides to adopt this policy, is there a process that the NDIA will use to achieve this reduction and can this be published? Who will be making this decision of approving or denying application of nominee status? Will the participant still have a choice to have a nominee? How will you measure the success or failure of such a policy? Will you take into account other effects of removing a nominee, on participants where they benefit or suffer in other areas of their NDIS Plan aside from the decision making area? And do you have a process to measure this if a nominee is removed or denied? If reducing nominees has been found to be detrimental to participants will you abandon this policy and will we be notified of the change?

Policies should not make the process of navigating the NDIS harder for participants and their carers. The proposed NDIA policy to reduce the number of nominees just reads as a target that Agency public servants will have to aim to deliver. This will be detrimental to families as so much of the administration and day to day running of the NDIS plan is done by a family member. It is my understanding that for a family member to access the NDIS portal on their own myGov account they must be a nominee. Cognitive impairments as well as poor executive function and fleeting attention spans mean that participants need practical support to not just make a decision but also to physically execute that decision which include payments, checking invoices, checking budgets, finding and contacting supports, communicating with everybody involved. Participants with autism lack communication and social skills, and may find it difficult to liaise with the NDIA, the LAC, the providers, the plan manager, therapists and anyone involved in the running of their Plan. My understanding is that removing nominee status will increase the complexity and difficulty for family to interact on behalf of the participant even if it is their decision to let someone else help.

Please consult the disability community, as it is my opinion that the policy of *reducing nominee numbers* is out of kilter with the other ideas of

empowering the participant in which the the spirit of the Supporting Decision Making is written.

Your sincerely

Plan nominee for her son

**Support for Decision Making consultation submission**

**Name:** Individual 1 (NSW)

**Date and time submitted:** 9/10/2021 6:33:00 AM

**How do you identify:**

* A NDIS participant: No
* A family member, friend or carer of a NDIS participant: Yes
* A NDIS nominee: Yes
* A legally appointed guardian: No
* A disability support worker: No
* A health or allied health worker: No
* A community member: No
* Aboriginal or Torres Strait Islander: No
* Culturally and linguistically diverse: No
* From a rural or remote area: No
* A person with an intellectual disability: No
* A person with a cognitive impairment: No
* A person with a communication disability: No
* A person with a psychosocial disability: No
* Other: No
1. **How can we help people with disability make decisions for themselves?**
* Resources: Yes
* Information: Yes
* Decision Guides: Yes
* Having a person help: Yes
* Other: No
1. **Who are the best people to help you (or a person with a disability) to make decisions?**
* Family: Yes
* Friends: Yes
* Peer Support Networks: Yes
* Mentors: Yes
* Coordinators: No
* LAC: No
* NDIA Partners: No
* Advocates: Yes
* Service Providers: Yes
* Other: No
1. **What should they do to help with decision-making?**

Lots of time and unhurried conversations with people who know you, problem solving and mind mapping, research and contact with peer groups

1. **How can they get better at helping?**
* Getting to know the participant well: Yes
* Doing some training on decision support: Yes
* By having resources and information about providing decision support: No
* Other: No
1. **How can we make sure the right people are helping?**
* They are chosen by the NDIS Participant as a decision supporter: No
* They value the rights of people to make decisions with support: Yes
* They are a registered provider: No
* They enable the participant to take risks: No
* Other: Yes

They have the best interests of the participant in mind

1. **What should decision supporters know about so they can better help people with disability make decisions?**
* Guidelines for decision supporters: No
* Scenarios or Examples: Yes
* Information Sessions: Yes
* Support Networks: Yes
* Other: No
1. **Can you tell us about a time when someone helped you (or a person with disability) to make a big decision?**

No

**What worked well?**

No answer recorded

**What could have been better?**

No answer recorded

1. **What is the best way to support people with disability to make decisions about their NDIS plan?**
* Practice: Yes
* Peer Support Networks: No
* Information and Resources: No
* Guidance Tools: No
* Not Sure: No
* Other: Yes

Having people who are familiar with the plan and with the participant support the participant

1. **Are there different things to consider for people with different disabilities or cultural backgrounds?**

**An intellectual disability:** Yes, The family should be given information and funding to have person centred planning (like PATH) to ensure that the participant has choice even if the person is non verbal

**A disability that impacts how they think, a cognitive impairment:** Yes, Insight and problem solving are a challenge (eg in autism)

**A psychosocial disability:** No

**A disability that impacts their ability to communicate:** No

**From a CALD community:** No

**From an Aboriginal or Torres Strait Islander Community:** No

**From the LGBTIQA community:** No

1. **How can we help reduce conflict of interest?**

Educating participants and families about circle of supports or micro-boards and funding them. I don't think more input from the Agency would necessarily be helpful.

1. **How can we help reduce undue influence?**

Educating participants and families about circle of supports or micro-boards and funding them. I don't think more input from the Agency would necessarily be helpful.

1. **What are your concerns (if any) around people with disability being more involved in making decisions for themselves?**

Only if the Agency mandates a reduction in nominees as a way to make this happen. Participants need even more support if they are to make decisions for themselves not less.

1. **What else could we do to help people with disability to make decisions for themselves? Is there anything missing?**

The whole process of dealing with the Agency is daunting and often adversarial for participants and until this is fixed the NDIA won't be able to help. The is an underlying problem of no disabled board or senior members on the NDIA - elect some to positions of decision making at the top and lead by example.

1. **Do you have any feedback on our proposed actions in Appendix C of the paper?**

No response recorded