**Support for Decision Making consultation submission**

**Name:** Individual 63 (VIC)

**Date and time submitted:** 7/1/2021 11:08:00 PM

**How do you identify:**

* A NDIS participant: No
* A family member, friend or carer of a NDIS participant: No
* A NDIS nominee: No
* A legally appointed guardian: No
* A disability support worker: Yes
* 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: No
* Other: No

1. **What should they do to help with decision-making?**

They need to spend the time to unpack and support the person to understand the decisions they are making. Communicating in a way that best suits the participant, but also ensures the time is there to revisit the decision until they make their decision

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: Yes
* Other: No

1. **How can we make sure the right people are helping?**

* They are chosen by the NDIS Participant as a decision supporter: Yes
* 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: Yes
* Other: No

1. **What should decision supporters know about so they can better help people with disability make decisions?**

* Guidelines for decision supporters: Yes
* 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?**

Yes

**What worked well?**

That my organisation gave me the time to spend with the person to develop the rapport, and to spend the time that was needed (which was alot) to assist them to make the decision to have their NDIS plan reviewed. I worked to develop a care team model with other paid supports and the paid accommodation provider to ensure the participant was fully supported in a safe manner (given that we were all paid supports).

**What could have been better?**

It was such a challenging process. Only one of the Victorian advocacy agencies would assist, the others advised that they no longer have funds for supported decision making supports. The one agency that could help had a long waiting list, and were only able to assist with the plan review. In the end they didn't assist as the review came faster than their waiting list. The other issue was the NDIS delegate that reviewed the previous plan removed support coordination (which hadn't been activated) and streamed the person back to the LAC. The person has no informal supports, a PND, intellectual disability and 2 psycho-social disabilities and lives in a SRS. The LAC is not able to ethically assist with supported decision making as a paid employee, and this participant needed full support (and lots of time) to choose supports, and sign service agreements (which they can't read, or comprehend). There are a lot of NDIS participants in SRS accommodation with no family and informal supports who have no impartial decision making supporters. It's terrible. It took almost 12 months to remedy this person's situation, and they are finally utilising their plan with support coordination, however, they still need impartial supported decision making, as this is not the role of the Support Coordinator (as a paid worker). Finally the other challenge is that this participant I am speaking of can't coordinate their supports, or manage a roster of supports, so this means accessing and cancelling supports is a big challenge for them.

1. **What is the best way to support people with disability to make decisions about their NDIS plan?**

* Practice: Yes
* Peer Support Networks: Yes
* Information and Resources: Yes
* Guidance Tools: Yes
* Not Sure: No
* Other: Yes

Funding more impartial decision makers, who aren't paid by the participant, and are not aligned with paid providers. This is a huge loss in support that was once there for pople with disability.

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

**An intellectual disability:** Yes, Communication approaches are key, as well as rapport, and time. It takes alot of time unpacking and supporting a person with an intellectual disability to understand the NDIS, what it means to and for them, and how they can navigate it, and make safe decisions.

**A disability that impacts how they think, a cognitive impairment:** Yes, Communication approaches are key, as well as rapport, and time. It takes alot of time unpacking and supporting a person with a cognitive impairment to understand the NDIS, what it means to and for them, and how they can navigate it, and make safe decisions.

**A psychosocial disability:** Yes, The cyclic nature of psychosocial disability is key to understand. I have people I have planned for who are almost impossible to reach (they have no phone or email due to florid paranoia) and they sit the NDIA, where they will be discharged from the scheme as they will be UTC. I have contacted the allocated delegates who have advised they are unable to assist.

I think with all the cohorts above another impediment from the perspective of the NDIA planners is that they don't home visit, or meet a person where they feel most comfortable. This is a huge barrier impacting people with a disability who are unable to attend an office or communicate over the phone.

**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?**

Fund independent supported decision makers. These roles used to exist and they've disappeared with the ILC and NDIS funded supports. It's a real shame. Hence my example of my own experience trying to find someone without a conflict of interest.

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

Fund independent supported decision makers. Again, I made sure I had a second worker in the room with me when I was working with the participant to ensure I was explaining things clearly, and wasn't pushing an agenda. I am really mindful of this. When I am working with other participants and I observe this behaviour I call it out in the room during the engagement.

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

There's no support for NDIS participants to truly access impartial supported decision making. It tool me months of calling OPA, VALID and a range of smaller advocacy agencies before I found one that has two part time supported decision makers that only help with reviews and that's it. I think there is too much emphasis placed on LACs and Support Coordinators to do this work, when really their role is capacity building not supported decision making. Especially at the level of support some PWD have who are vulnerable and living in unsafe accommodation (such as the SRS/boarding house sector).

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

Give time to PWD to develop their decision making skills, fund impartial supported decision makers, do more work mapping vulnerability and need for supported decision making n the SRS and group home sectors, revisit and revise the communication/consent channels for Support Coordinators into the NDIA. This is so broken and prevents proper communications when there is an issue.

Finally, with the participant example I provided in this submission, they had their second planning meeting over the phone. The delegate significantly reduced the supports and streamed the plan back to the LAC. The major concern with the delegate decision is that this participant cannot communicate over the phone, and the person they spoke to was an unauthorised contact (who they had no consent to speak with), yet they completed the plan review under these conditions. Very bad outcomes that took almost 12 months to remedy.

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

I think this is a strong place to start, but again I think that the supports need to be impartial and the providers not be NDIS funded directly. Also with people with psychosocial and intellectual/cognitive disabilities there needs to be alot of time to develop trust, rapport and space to develop the skills. I think there is also the remaining issue of coordination of supports for people who aren't able to coordinate their supports (right down to booking/cancelling daily supports ) without intensive support (who are not eligible for SDA/SIL).