**Support for Decision Making consultation submission**

**Name:** Individual 57 (VIC)

**Date and time submitted:** 7/5/2021 9:52:00 AM

**How do you identify:**

* A NDIS participant: Yes
* A family member, friend or carer of a NDIS participant: No
* A NDIS nominee: No
* 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: Yes

Have alternative means of communication readily offered to each participant- ie being able to write down responses, use alternative communication. This is best achieved face-to-face

1. **Who are the best people to help you (or a person with a disability) to make decisions?**

* Family: No
* Friends: Yes
* Peer Support Networks: No
* Mentors: No
* Coordinators: Yes
* LAC: No
* NDIA Partners: No
* Advocates: Yes
* Service Providers: Yes
* Other: No

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

'translate' what I'm trying to say. I have autism and sometimes don't quite say what I mean. I find it helpful if someone can rephrase what I'm saying and ask "is that what you meant?". It is also really helpful to have someone to advocate when I'm on the verge of having a meltdown to ask for breaks. It is also helpful to have someone else's perspective on what i need. I don't always know what I need.

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: Yes

It would be important to ensure that certain (big companies etc) don't strategically manipulate the system and ask for more/specific supports for a participant in order to gain more profit. I think this is far less likely from smaller more individualised providers who genuinely seem to care more about their clients than profits. I also don't think there should be any restrictions placed on people who voluntarily or independently advocate for clients (who do not personally stand to profit from any funding granted)

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?**

My psychologist advocated for me (and wasn't paid) during my first planning meeting. It was helpful as she knew my needs and asked for specific supports to be included. I had no idea what to ask for. She was also able to help communicate to the LAC that I was becoming distressed during the meeting (having a meltdown) and was able to advocate for me through this.

**What could have been better?**

Having enough information before the meeting (questions that would be asked) and a chance to talk over this freely with my support person before being able to forced to give answers on the spot during the planning meeting

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: No

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

**An intellectual disability:** Yes, People with ID don't always know their own limitations. For example, a young man I met at uni had a mild ID but had no chance of passing a bachelor degree- they were setting him up to fail. Whoever allowed this was allowing him to pursue his goals yes, but it was not realistic and a waste of tax-funded tuition fees. It would have been better to consider his preferences, but still only allow realistic goals to be set (allow choice and control but safeguard decisions using common sense)

**A disability that impacts how they think, a cognitive impairment:** Yes, Preferences should be considered, but important decisions should be safeguarded. This also applies to people who have cognitive impairments and have poor insight to all (or some) areas of their function and needs. They should not be expected (or allowed) to attend without someone to help- if they do (or are forced to) they may not accurately articulate their needs and get appropriate services and funding budgets.

**A psychosocial disability:** Yes, A trauma informed approach should be considered. It may not be in the person's bets interest to be bombarded with personal questions about functional limitations. They may not even be aware of, or may be in denial of having a problem, and may not articulate their needs well enough to gain the supports they need. However, preferences would be a vital aspect for this group as this can help facilitate a sense of control, especially where goals are concerned.

**A disability that impacts their ability to communicate:** Yes, Having different options of communication available right from the get go. The fact you basically need to ring the NDIS to start the application is very daunting, and poses a communication barrier for some. It would be great to see an online application form (similar to Centrelink) where you can simply upload supporting documents at the time of the application (and take as long as your need to complete it, with the option to save and come back later). There also needs to be options for braise, auslan, augmentative communication, and other forms of communication such as writing down answers as a way of communicating with he NDIS. Phone calls are simply not cutting it. They are daunting, the staff member can't see and therefore has no way to respond to participant distress, or see non-verbal cues that aid in communicating. Face to face NEEDS to be an option for anyone who needs it (even during COVID) and other communications styles catered for.

**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?**

Indpendant advocacy (properly funded) should reduce this risk. This could be done by having a meeting between the advocate, the participant and service providers before the planning meeting to agree upon what the clients needs are, and what is in the participant's best interests (and what the participant wants).

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

Train NDIS staff to recognise this if it occurs during interviews, and be trained in how to respond to this (ie ask the supporting person to let the participant talk and then address the participant directly etc).

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

It's not a one size fits all. Some participants can effectively advocate for themselves. Others can't at all. Still others have overbearing support persons who are trying to help the person but are too controlling, still others are falling through the cracks receiving no advocacy when they really need it (and suffering inadequate or inappropriate support as a result). Better training is needed for NDIS staff to identify which category each participant may fall under. Also, a lot more funding for independent advocacy would go a long way. To option to having a supportive person with them (or have independent advocacy arranged for them) and communication style/preferences should be asked at the start of every conversation with an NDIS staff worker. My communication needs have been under recognised by NDIS staff in past, to the point where I was coerced into inditating a review- a review that I later needed to stop/pause because I couldn't answer the questions on the spot, and I had no-one to support me in that moment. Should anyone be forced into that circumstance (and I'm considered 'high functioning')?

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

Loose the jargon. Put info in pictures, use typical scenarios, have multiple short interview sections to make it easier for the person to cope.

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

No response recorded