**Support for Decision Making consultation submission**

**Name:** Individual 2 (NSW)

**Date and time submitted:** 9/10/2021 5:34:00 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: Yes
* 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: No
* Other: No

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

Spend time getting to know the person well so they understand their likes and wants, hopes and goals. Assist the person to understand available options and to express their preferences and choices. the

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

Registered providers should not have this role. There should not be payment., inducement involved only the best interests of the person. No service providers.

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: Yes

people need to understand what is possible before they are able to express their preferences.

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?**

The person with a disability was placed in an aged care facility at age 18 by her parents who had no contact since birth when she left residential school. her advocate who she thinks of as mum fought for 4 years to get her funding and out. The person with disability was so depressed she was refusing food.

**What could have been better?**

The funding system could have given options without advocate having to take legal action and grab first accommodation option out of desperation. The fact that the person with disability was trying to kill herself through food refused should have been sufficient proof of her desire rather than biological parents who had no involvement in her life being decision maker.

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

The reality is NDIS plans are determined by planner and services not participant with disability

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

**An intellectual disability:** Yes, More time is needed to hear the voices of people with intellectual disability. It takes time to understand what is possible, then to understand what options and preferences the person chooses. This is particularly relevant to people who are not verbal. Specific strategies to present information in comprehensible ways , including multiple formats. My daughter for example, has intellectual disability is non verbal, blind and uses a wheelchair , opportunities for her to express her choices take time and trial and error to tease out.

**A disability that impacts how they think, a cognitive impairment:** No

**A psychosocial disability:** Yes, A flexible approach that accommodates that some psychosocial disabilities fluctuate in the impact is needed. This is a weakness in NDIS plans and with planners.

**A disability that impacts their ability to communicate:** Yes, Time taken, different formats , repetition

**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?**

Decision making supporters should NOT be service providers. There needs to be independence.

SIL funding discussions should be separate from participants planning meeting . The focus is ALWAYS on service support needs in NDIS planning meetings which takes away from participants opportunity to express their decisions , goals etc

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

See above.

I have had direct experience of accommodation service provider threatening the NDIS participant with being exited from their accommodation if the did not support increase in SIL Funding with NDIS.

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

That supporting participants with decision making becomes a paid role and new way for service providers to make money.

That it is done in tokenistic way so that participants are not given time and experience to make real choices.

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

Yes a hierarchy of need training for people with disability and their supporters to consider how to maximise the chances that voices of people with disability are heard directly and to consider how to determine what supports a person might best need to support their decision making with a focus on least intrusion possible. Giving people with intellectual disability and others as appropriate as long as needed to understand their choices.

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

Goal 1 needs to focus on skill building for participants not just providing information, particularly written information that is inaccessable for people that have intellectual disability, or others , who cannot read.

Goal 2 excellent idea provided in includes changes with ageing etc and is not used as tool in plan funding

Goal 3 likewise , most decision makers supporters agonise over whether they are making decisions that participant would make

Goal 4 opens up the risk that there is no voice other than NDIA or Service Providers supporting people with disability.

It would be better for Nominees to report on opportunities for people with disability to decide and how this worked this gives the opportunity to see the gaps . Reducing Nominees is NOT evidence that people with disability are making decisions unless that is the decision of the participant.