**Support for Decision Making consultation submission**

**Name:** Individual 26 (SA)

**Date and time submitted:** 8/25/2021 12:27:00 PM

**How do you identify:**

* A NDIS participant: No
* A family member, friend or carer of a NDIS participant: Yes
* A NDIS nominee: No
* A legally appointed guardian: No
* A disability support worker: No
* A health or allied health worker: Yes
* 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: No
* Information: No
* Decision Guides: No
* 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: No
* Coordinators: Yes
* LAC: No
* NDIA Partners: No
* Advocates: Yes
* Service Providers: No
* Other: No
1. **What should they do to help with decision-making?**

People who are close to participants know the needs of the participant and should be listened to by the planners. So far experience is NDIS has no idea of what participants need and don't listen.

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: Yes

Have solid knowledge of background of disabilities for participants. Be health professionals not Cert IV trained people. Nurses are in the ideal position to make decisions for planning that is what they/we do all of the time for patients and clients. I am a carer and also a health professional of over 40 years experience NDIS under values nurses expertise.

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: Yes
* They enable the participant to take risks: No
* Other: Yes

some providers are dodgy like the one who didn't look after that woman who died. All support workers must have in depth knowledge and expertise there are too many inexperienced people. Also matching with participants is important so there are no cultural barriers or language barriers.

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: No
* Information Sessions: Yes
* Support Networks: Yes
* Other: Yes

As an experienced nurse over 40 plus years and about to retire I am not impressed with how the NDIS works. There needs to be collaboration between providers, support workers and other services such as within SA Health who provide care and service to participants. The communication lines are broken and this needs to be fixed immediately to reduce risk to participants.

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 participant and I transitioned from a support network prior to NDIS coming in to being and they and us transitioned to the NDIS together. It went smoothly and we are preferring to stay with that provider as we trust them and they are a strong provider and of long standing in South Australia.

**What could have been better?**

NDIS listening to the needs of the participant and listening to me the carer about the needs of the participant. There are not enough activities provided by NDIS they just seem to provide support worker networks. The information about NDIS is vague in terms of what is available

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

As above Nurses should be employed as Nurse consultants to direct the allocation of providers to participants so they are well matched. Don't use the Cert Iv people they don't have experience.

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

**An intellectual disability:** Yes, There should be accurate matching of services given if the wrong LAC is appointed or chosen then the wrong types of support can occur and I've seen this in the position I hold as a clinician. It takes a long time to undo the harm, the mess, and organising NDIS for clients is not my role nor do I have time. Also need to have people who understand traumatic and acquired brain injury which is my role as a carer. I've done a national survey and started a PhD on resilience for carers and there are so many unmet needs it is saddening. NDIS don't understand living with brain injury, the carer role, nor the needs of the participant or the carer. This needs to be built upon in a large way. Happy to help and be consulted given my expertise and multiple academic degrees.

**A disability that impacts how they think, a cognitive impairment:** Yes, As above align the disability with the provider and support worker so that expertise are carried over to provide competent and safe care to participants.

As before having a CertIV is not enough. There has to be a high payment to workers and an expectation expectation they will undertake a university degree to align care provision to participants. If Cert Iv's must be employed they need to have competent English, be prepared to engage in continual learning, and develop expertise to the particular area of disability they are working in. The current method is thin on the ground in terms of knowledge and English language capabilities.

**A psychosocial disability:** Yes, Workers need to know what places to tap in to for psychosocial interaction. this needs to be consistent, dedicated and ongoing.

**A disability that impacts their ability to communicate:** Yes, Workers needs to learn to communicate with participants as this is important. Depression is major when communication is unable to be achieved. Devices need to be provided to participants and workers need to know how to use them and encourage use. Also developing jointly with participant and support worker other methods of communicating so there is a rapport built between them. If different workers have to be used then a team needs to be formed and introduced to the participant so they are comfortable with different workers. don't just drop them in.

**From a CALD community:** Yes, CALD participants should have people of their own culture/language it is unrealistic to expect CALD to feel comfortable with workers who don't speak the same language or understand the culture. it is disrespectful as well.

**From an Aboriginal or Torres Strait Islander Community:** Yes, Likewise as above and workers must be compatible and of the same culture. If possible the same mob. It is disrespectful to expect them to feel comfortable with a white person or other culture worker and they deserve to have their own cultural care. (don't get me started).

**From the LGBTIQA community:** Yes, No person who does not belong to this particular population of participants can understand the dynamics and therefore it has to be support provided by workers who are of the same groups. Again disrespect and judgemental attitudes can interfere with rappor building.

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

I am a carer of a participant who we have known each other since our young teens. It would be extremely incorrect for me to become an NDIS provider/worker in order to care for the person I care for and do the work I do in my employment. I have strong views on keeping lines separate and conflict of interest should never ever be part of participant support. The person I care for has NDIS support workers as above through an agency we started with prior to NDIS and I found them.

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

This is highly illegal and beyond the scope of practice and must never occur. Participants should not be exploited, manipulated, or coerced. EVER

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

Cognitive impairment has concerns because these participants can agree to something they don't understand. Advocacy is very important in this aspect. Also I disagree with self managed funding. Funding should be indirectly managed to avoid participants spending the money for other purposes other than what they are intended - care and support.

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

Yes- LISTEN, know the areas of disability, don't judge people. Example people who receive compensation and become wheelchair bound then are told they are not eligible for NDIS because they received compensation. This is wrong. They are entitled to NDIS support the same as anyone else. Because they received compensation doesn't mean they are rich. It means they have funding to provide them with the ability to buy equipment, buy appropriate clothing they need, travel where they want to and have occasional social interaction they can afford. NDIS should never be withheld because "compensation" was received. These people didn't ask for an accident or injury to occur they were in the wrong place at the wrong time and by withholding NDIS and telling them they have to pay for services then they are being denied basic humans rights. NDIS falls very short in these cases and I've seen at least 4 since NDIS came in to being. You can not judge people like this they have been through as much trauma and disruption as anyone could bare and NDIS adds to the trauma and makes people relive the trauma by antagonising them about withdrawing or denying NDIS support.

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

Just get it right. provide NDIS support to all who require it. Don't judge, don't discriminate, and match workers with cultural needs and language and ensure they are adequately educated and not just a Cert IV in whatever. They must have expertise in specific fields of care and nurses must drive the allocation of supports and LAC's because nurses are a primary source of high level expertise but they too must be experienced with at least 5 years experience in clinical settings prior to being suitably able to be employed no use employing a university graduate in to an area of NDIS allocation they don't have experience. I have 44 plus years of experience and I an constantly annoyed at the lack of expertise I seen in the care arena. People must be suitable experienced and qualified. I'm happy to provide input at any time given my national survey and responses from carers of people with traumatic brain injury and my expertise in this area as well as mental health. christinespryor@gmail.com you will find my expertise on SEEK.com.au I also tutor at Flinders University and have many years experience in tertiary teaching.