**Support for Decision Making consultation submission**

**Name:** Individual 30 (NSW)

**Date and time submitted:** 8/20/2021 7:54:00 AM

**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: Yes

Ensure supporters understand how to build a persons ability; recognise undue influence/conflict of interest in themselves; can identify a persons strengths and ensure people are given the opportunity to make decisions. Plans should have goals that relate to building ability and specific strategies in place to do this.

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: Yes
* LAC: Yes
* NDIA Partners: Yes
* Advocates: Yes
* Service Providers: Yes
* Other: Yes

Everyone is a potential decision supporter. Ideally a persons informal network will be utilised first (if this is what the person wants). The supporter should be chosen by the person as different decisions will require different people/skills.

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

Start with the persons strengths; take context into consideration (eg trauma); provide 'just enough' support; set their own biases aside; be driven by the persons will and preferences; provide practical and psychological support; be funded with enough TIME to practice support for decision making. Know the skills of decision making so they can build a persons ability.

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 SDM as a core component of their skill set/job. People need to be trained and accredited in SDM as part of person centred practice. Good training in this area is an important safeguard as we are asking 'supporters' to do MORE with less oversight. The human rights and values that underpin this practice will be important for people to really understand.

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

By making part of a persons plan what 'skills' they need to build around particular goals/decisions; a better match of who should support them might be made.

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 the concept of risk enablement as part of SDM. They need to understand that nominees/guardians/financial managers are last resort and restrictive options that remove a persons decision making autonomy. Nominees are particularly problematic as they have few safeguards around them for monitoring or review. By practicing good SDM, the supporter is upholding a persons human rights and helping them avoid punitive, restrictive and oppressive substitute decision making regimes.

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?**

Resolving family conflict. Most matters that end up at court/tribunals relate to disputes between parties/families over what everyone considers is in the 'best interests' of a person. This conflict is often a significant contributor to the persons cognitive decline due to the stress and loss of their voice in this situation. Early and tailored mediation where the person is supported to genuinely participate in the session can reduce conflict and remind all parties what the person wants (including what support they need). Relationships Australia has a program that can facilitate this.

**What could have been better?**

Early intervention. SDM is a proactive and empowering approach that has the person at its heart. This is how our First Nation communities have always made decisions and we could probably learn a lot from them in this area.

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: No
* Not Sure: No
* Other: No

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

**An intellectual disability:** No

**A disability that impacts how they think, a cognitive impairment:** Yes, Capacity / ability should always be assumed and support provided where needed (guided by the ALRC National Decision Making Principles that are simple and eloquent). A move toward a medical model of assessments by allied health to determine if a person has 'capacity' is a dangerous slide away from empowerment. The many factors that impact on a persons ability (stress, MH, time, others, medication etc etc) should always be considered when providing support.

**A psychosocial disability:** Yes, 'Capacity' or decision making ability may fluctuate. Early intervention during periods of wellness can be used to help the person determine the particular type of support they need and want in situations where they may need extra support or even substitute. These conversations need to happen early, regularly and in a safe space by skilled people who the person knows and trusts.

**A disability that impacts their ability to communicate:** Yes, Everyone can communicate and the time and expertise needs to be applied to reveal how. At the heart of SDM is knowing the person; this cannot be done if we don't unlock how a person communicates and interacts with the world.

**From a CALD community:** No

**From an Aboriginal or Torres Strait Islander Community:** Yes, We can learn a lot about providing support from this community and any work in this space should be done in a co-design format. Supporting a person may not be done in an 'individual' way but support may need to be extended or shared with community.

**From the LGBTIQA community:** No

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

Help people and organisations understand what it is.

Ensure the NDIS is not facilitating this by allowing providers to over-service rather than build ability and skills.

Hold Service Providers accountable if they claim they are skill building but the person shows no evidence of gains.

Educate people with disabilities to identify COI.

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

Help people and orgs understand what it is.

Work with organisations on 'cultural change'.

Educate people with disabilities to identify this in their support workers/ life.

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

Nil

Lots of people worry about risk or people making 'poor or wrong' decisions. We are all supposed to make mistakes and have the right to do so. Supporters need to be helped to think about risk as a positive and understand how to mitigate risk with a focus on a persons strengths and preferences.

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

Consider stop talking about capacity and talk about ability or capability. 'Capacity' is the realm of the medical /legal world and can result in a person being regularly assessed in an intrusive and expensive way when less restrictive options are more appropriate.

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

Commit to training NDIS/NDIA staff/providers and people with disabilities and their supporters. This is a cultural change and a shift in thinking that moves away from paternalism to empowerment. This is a challenge for many people to embrace.