**Support for Decision Making consultation submission**

**Name:** Individual 24 (NSW)

**Date and time submitted:** 8/26/2021 4:28:00 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: 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: 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: No
* Mentors: No
* 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 know the person well, be commited, and put that person's interests first, even if it is personally costly to the supporter, is by far the most important. The higher up the food chain the greater the liklihood that the decision making will be unduly influenced by assumptions and stereotypes rather than a person's actual choices, stereotypes.

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: No
* Scenarios or Examples: Yes
* Information Sessions: No
* Support Networks: No
* Other: Yes

If nothing else they need to know and value the person well and be accountable. In most cases this is friends and family. Knowledge and skills are important but not as important as knowing, valuing and commitment.

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 son wanted to leave the family home like his sibblings did. No one else including all the "experts" thought this possible. I supported him in this decision, and reassured him that this would be safe and comfortable.. I understand my son's hopes and fears more than anyone. I also understand his communication style. This made it possible to support him to make this momentous decision. Not all of the fine detail was sorted but when the opportunity presents you need to be brave and act.

**What could have been better?**

We didn't have the night time support worked out but we took a risk and it turned out he didn't really need it and he is still there after 14 years.

1. **What is the best way to support people with disability to make decisions about their NDIS plan?**
* Practice: Yes
* Peer Support Networks: No
* Information and Resources: No
* Guidance Tools: No
* Not Sure: No
* Other: Yes

Make sure the NDIA planner is really listening. Once again know and value the person with disabiliy and make sure that persons needs are in the plan before the planner leaves.The plan needs to be sufficiently flexible to accommodate all of the persons needs and to change when those needs change. People with unusual brains unsurprisingly have unusual needs and desires which NDIA plans and planners have difficulty understanding or accommodating. As a result plans can be loaded up with unhelpful stereotypical goals.

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

**An intellectual disability:** Yes, That I have 3 boxes to complete suggests the undue influence of the medical model. People with unusual brains see and experience the world differently. (I don't think the NDIA fully appreciate this. An example is requiring participants to attend a planners office for a plan review because it is supposedly a WHS issue even though it is known that some participants will be very stressed in such circumstances. Strangly this WHS issue doesn't apply to LACs.)

People with an intellectual disabiliy and a cognitive impairment won't necessarily understand what is being said or requested particularly if it is nuanced or complex. How, where and by whom it is said also matters. The importance of matters may also not be appreciated. They may experience sensory overload, and be easiy distracted. Visually might be more important than auditory. They can get "stuck". We often make incorrect assumptions about what they mean or feel. Like all of us they need to be taken seriously even though they might not appear serious. They need support and collaboration. All of these things are difficult for people who don't know them well to appreciate, understand and act on.

**A disability that impacts how they think, a cognitive impairment:** Yes,

**A psychosocial disability:** Yes, Many people with an intellectual disability like my son experience extreme stress and anxiety. This can result in difficult or unusual behaviour. It needs to be assumed that their behaviour is reasonable in the circumstances they are in. The behaviour means something. They are using the behaviour as a solution to something. Again, all of these things are difficult for people who don't know them well to appreciate, understand and act on.

**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?**

Everyone and their organisations has a conflict of interest. Families are likely to have the least conflict of interest and organisations, particularly large ones, the most. People with disabilities who have families in their lives are likely to have the best lives. Everyone needs good information about what constitutes the good life. They also need information and probably guidance in recognising conflict of interest, because we all have it, and how to address it. Taking the greatest notice of people who are voluntarily in a person with disability's life, and who know them best, is a good place to start.

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

Trying to get as many people as possible in the life of a person with a disability. Making sure there is more than one person attentive to the welfare of a person with a disabilty. Usually this is a family member. Remember that people are fallible.

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

Many people with intellectual disabiliy don't always make good decisions and so need some guidance. However, they need the opportunity to make decisions . Support might be or akin to guidance rather than direction. More direct interventions might be where their decisions create physical risk, unmanageability, limit the goodwill of others, get them into trouble or diminish their worth in the eyes of others.

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

No response recorded

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

Part of the thrust of Appendix C seems to be producing guidelines, best management practices and the development of individual inventories of support (goldmine for consultants?). It is then assumed that this would reduce the number of nominees. What seems to have been forgotten is that it is likely that the people closest to the person with disability are likely to know them best. These people (the coal face) are likely to be families, friends and the relevant paid people being support workers. Unless the coal face is fully utilised in producing guidelines, best management practices and the development of individual inventories of support they will end up being mostly the products of "experts" and senior people in the food chain. "Experts" and other senior people have much knowledge and skills to offer but where they fall down is in bringing what they know down to the needs of individuals with disability. To date we have too many "cut-and-paste" reports that are expensive and rarely implemented. The idea of a performance indicator of a "reduction in nominees" rings alarm bells. What is needed is process that integrates the knowledge, skills and commitment of both the "coal face" and the "experts". Otherwise we will end up with an increase in formal decision making that takes little account of the humble dreamings of a person with disabilies.