**Support for Decision Making consultation submission**

**Name:** M2M (NSW)

**Date and time submitted:** 8/13/2021 2:12:00 AM

**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: 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

Personalised Journey Map

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?**

Keep the persons realistic goals at the centre, guide the person regarding the major decisions which have significant impacts on their life (education, social inclusion, what they might need to study to enable their work opportunities, housing, financial and legal support)

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

Having a means of capturing data (write once-use many) about the PwD (with a smart checklists to guide them) for various stages of their life and their needs would be the most accurate and empowering way for a PwD and their carers to manage and track supports and measure actual outcomes.

1. **How can we make sure the right people are helping?**

* They are chosen by the NDIS Participant as a decision supporter: No
* They value the rights of people to make decisions with support: No
* They are a registered provider: No
* They enable the participant to take risks: No
* Other: Yes

The participant needs to identify their goals with their support person (if they can't do it themselves) and then practitioners can validate achievement of milestones and make recommendations fo9r revised goals or revised supports.

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

They should be able to articulate and capture the participants goals and understand what facilities and supports are able to help achieve those goals. They would need to prioritise goals to ensure the best quality of life for the participant across a number of categories: personal health and well being, continuous learning, employability, social inclusion, housing....

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?**

Identifying what the participants goals were, talking through what the stages were to get there and what they would need to do to get there and what they might need support to get there.

**What could have been better?**

Having a better understanding of what supports were actually available and being able to connect to others with like goals and similar circumstances.

1. **What is the best way to support people with disability to make decisions about their NDIS plan?**

* Practice: No
* Peer Support Networks: Yes
* Information and Resources: Yes
* Guidance Tools: Yes
* Not Sure: No
* Other: Yes

Trusted advisors in my local community

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

**An intellectual disability:** Yes, They can be at risk for being taken advantage of and can have unrealistic goals and views. There are limited employment opportunities in the current climate.

**A disability that impacts how they think, a cognitive impairment:** Yes, Specialisterne would be better responding to this but they are also at risk of being exploited.

**A psychosocial disability:** Yes, Setting up realistic, achievable goals and strong support networks

**A disability that impacts their ability to communicate:** Yes, Finding ways through technology to enable communication

**From a CALD community:** Yes, duh - understanding their cultural differences and biases but also understanding what aspects of those they accept/wish to comply with or change

**From an Aboriginal or Torres Strait Islander Community:** Yes, I've not had experience with this but would assume it's a few things from CALD

**From the LGBTIQA community:** Yes, Being accepting and non-judgemental but also realistic

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

I have always thought communities of trust, micro-boards and families checking in on each other is vital to the ethics and efficacy of services and supports. Also outcomes must reflect actual quality of care, support or achievement of goals. Being able to have a clear path of escalation and occasional review important. Allowing observers to call out and observe suspicious behaviours through a reporting system (like crimestoppers or an uber-like evaluation of services) would be a good start.

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

For example Apple watches and other biometric technology organisations are working on tools to improve quality of care and health checks - might seem expensive but may potentially be far more cost-effective (and potentially less invasive) than other alternatives.

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

My daughter has ID, no concept of money, socially isolated - she can make many decisions for herself but could be at risk if she is manipulated by someone who does not have her interest as a priority. I have 3 members of the family with very different interests involved with decision making for critical matters like banking, insurance, education. She has worked hard to earn $7,000 but nearly spent $1,000 to buy a surfboard on line and would have if she had free access to all her funds.

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

I'm a fan of a circle of support and smart tools which include a life journey and plan that my daughter can manage her money, her goals, and activities with support from people who have her interest at heart. I also think connecting with a community of parents and other PwD can be a great support for shared learnings but we need to make sure there are no predators in those communities.

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

Spot on - I would prefer to see the terms - educate, empower and enable somewhere in there. Well done. Very excited for you and the team. Someone is actually talking WITH us not AT us. Thank you.