**Support for Decision Making consultation submission**

**Name:** Individual 23 (SA)

**Date and time submitted:** 8/26/2021 1:03:00 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: 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

Understand the person with disability; know best way can communicate with person. Have understanding of UN Rights of the person with a disability, and National Disability Strategy. Understand the life stage of the person.

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: No
* Advocates: Yes
* Service Providers: Yes
* Other: No
1. **What should they do to help with decision-making?**

Disappointed with Local Area Conordinator, who, after submitting information about NDIS participant, and supporting documents, simply rolled over the previous year's plan for another year. Then when looked at plan, found NDIS participants goals had not been updated, as the particpant's had reached young adulthood, and the goals were from when participant was child. Disappointed and upset as realised LAC had not even looked at documents had written, which included new goals for participant. Then because when asked if was happy for plan to proceed, stated that wished for new goals to be in new plan. And than for some unknown reason, a new plan was created, which cancelled the previous plan, and funding for services that were supporting chiild to develop skills to help with communication and motor skills halved and funding for Behaviour supoort tripled over an incident at participants school. This is not person centred planning; The LAC has not met or communicated with the participant, the participant has allready been judged to require to be treated rather than to be supported to develop skills that will help participant.k So many promises, yet even with the NDIS, let down at every life stage so far. Lot of waste.

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

Such as human centred design; working with the participant rather than passing judgements and making decisions on what LAC thinks is best for participant, without even having met or informing participant until after make disruptive changes that require more time wasting and stress by participants family, having to chase up providers and re-sign contracts, and cancel bookings because funding not available anymore, and have funding for services that don't require or want, and will not make any better outcome, but which providers will provide because they know money is there.. Have some cultural understanding.

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: Yes
* They are a registered provider: Yes
* They enable the participant to take risks: No
* Other: Yes

Why do you want to enable the participant to take risks when the participant is not aware of the risks from the decision made, and if there are risks then it is the responsibility of providers, carers to prevent harm.

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

UN convention of the rights of people with disabilities, National Disability strategy, Shut out report.

1. **Can you tell us about a time when someone helped you (or a person with disability) to make a big decision?**

No

**What worked well?**

No answer recorded

**What could have been better?**

No answer recorded

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: Yes
* Other: Yes

Human centred design, Applying principles of service design. Because at the moment, there is no credible, constructive support by the NDIS.

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

**An intellectual disability:** Yes, The means of communication, if communication board (which some providers have denied) devices so that able to achieve their optimum means of communication, so that they are denied the opportunity for their voice to be heard.

Time; spent to get to know the person; when the NDIS can give a service provider $500 to spend 45 minutes to do an assessment and charge $500, and then write a one page assessment that has no plans to guide the participants future plans/goals is a joke, and the joke is on people with disabilities, and the people who genuinely wanted the NDIS to work and to make a difference to the lives of people with disabilities.

**A disability that impacts how they think, a cognitive impairment:** Yes, How did the NDIS get rolled out without first answering this question; why are you waiting till now to find this answer, after millions of dollars have been wasted, and most people no better off, and with limited futures. It's obvious that the cart has been rolled out before the horse, and with so much money making these service providers rich beyond their means and the disabled community no better off.

**A psychosocial disability:** Yes, Holistic outlook and view.

**A disability that impacts their ability to communicate:** Yes, As above.

**From a CALD community:** Yes, Cultures, traditions some that support inclusion of person with disability as family/community member, but some that shun person/family because has disability.

Cultures where will only allow family member to be carer, especially if woman with disabiility.

**From an Aboriginal or Torres Strait Islander Community:** Yes, Safety of the person first. Sometimes traditions/cultures can be harmful and disempower and threaten the wellbeing and safety of individuals. However, being told what to do and how to do things in a bureacratic way will not help or support persons to

**From the LGBTIQA community:** No

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

Well there is definitely conflict of interest with the NDIS, and like any other bureacratic government department, it would probably involve more enquiries and reports while the people for whom this organisation was created are no better off.

The inequalities begin to appear when service providers are given the privilege to charge for services not offered when they are notified three days in advance of a cancellation; yet the service provider is able to cancel on the day the service is booked, regardless of the inconvenience of plans made to attend session. So whose voice is is being heard here?

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

Support workers need to be monitored, and measures need to be in place so that regular (quarterly) meetings with the person who is supposed to be supported can be made, with an NDIS advocate, and be given the opportunity to communicate in a non-threatening environment, how they are going. And if the person is not able to communicate, then the health of the person should be regularly monitored and a data base be made so that can monitor if there is any deterioration in health including mental health/emotional health, and the environment the person is living, and the circle of people in the person's life.

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

I am concerned that they are not given the time or opportunity to have their voices heard; understanding that expressive and receptive communication may be limited. But all people have personalities, feelings, We must ensure they are being properly looked after, and if not, be put in an environment where this is possible.

Children should be given the opportunity to attend inclusive school environments; however, the infrastructure or willingness to allow them to be safe and to participate in these environments is not there, as they are considered an inconvenience in environments where the emphasis is on high achievement being rewarded. So even if the person with disability, such as the participant I am supporting wanted to attend mainstream school, the promised supports never came in time for this to be possible, even with NDIS funding.

Now the same roadblocks and lack of services to achieve independence skills is occurring again.

Only last week had meeting with large disability organisation who's website advertises life skills, mentoring; when had meeting, took note of amount of funding received. When asked if funding would provide for life skills and mentoring was told no, funding (over $30000) would only cover psychology and behaviour plans); well have had previous behaviour plan that is just collecting dust. So it seems with all the rhetoric and promises, the NDIS is really just about fixing and controlling the person, finding and reporting on what is wrong with the person, and then charging further to write more reports on how to solve the problem of the person.

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

A lot,.

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

Will read further on this, but from what currently experiencing, remain cynical