# **Feedback on Supporting you to make your own decisions**

Additional comment for consultation questions to answers within the online survey.

How can we help people with disability to make decisions for themselves?

The answer is different depending on who is meant by “we”. Assuming it is the NDIA as the administrator of the NDIS than there needs to be recognition that the role of funding via the NDIS plan is only an enabler and of itself doesn’t have an impact of the day to day experiences of the participant. Day to day experience is impacted by the beliefs, values and practices of the family, other informal supports, community, mainstream supports and formal supports paid from their plan. The extent to which these are the major or minor influencers on the way in which the participant is encouraged and supported to make their own decisions in the everyday and therefore builds their experience and confidence for the bigger decisions varies hugely. This variation has many determinants including culture, age and experience of family, previous involvement with services which often are more influential than type or extent of the individual’s disability. The NDIA through staff and partners has a very limited opportunity to help people with disability make decisions for themselves as they have very intermittent contact that is often not face to face or in the participants own environment and there is very limited continuity over time so each contact relies heavily on written material from a formal service of some type.

The options presented by the survey are all relevant however require a significant investment to incentivise and encourage their implementation by all the stakeholders mentioned the previous paragraph. To date there is limited evidence of this being undertaken by NDIA or even as being within in their mandate.

1. Who are the best people to help you…
2. What should they do to help you with decision making.
3. How can they get better at helping.

The answer is “ It depends “. For example the person for whom I am a partial Guardian and Plan Nominee and who spent the years from age 4 to 40 in state disability services with very limited family contact her only option was the service provider. When the system came into place she was appointed a Plenary Guardian by the State. In parallel I moved from being a service provider manager of her services to a personal friend and advocate and began a long process of enabling her will and preference about how and where she lived to be heard. In the last ten years there have been other decision supports come into her life that are both informal ( boyfriend, friend, advocate ) and formal ( staff member who has supported her for 10 years in her own home ). She has been supported to build her decision making capacity to the point that Plenary Guardian was no longer required. I am now a partial Guardian and also informal support. The mix of who are the best people to supports every person with disability is different and changes over time. As a fundamental premise it starts with those who love and care about you . However these people need to have the belief that you are a person with rights to make decisions and this involves exposure and knowledge from a very wide range of sources. Our state systems of Guardianship exist as a safeguard for those whose close supports are abusing or neglecting the person with disability or for whom there is no one to assist decision making for which they are not equipped or supported. It is better than not having this safeguard but far from ideal for most people as the Guardians appointed from the formal system often have very limited to opportunity to have contact with and know the person and therefore cannot be an effective decision supporter.

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

While I have ticked ‘They value the right for people to make decision and they enable the person to take risks” it is very difficult for an NDIA staff member or partner to make a judgement about these matters. As noted in 1. above they have limited contact and also limited experience. The basic starting point is are there informal or formal people in the participants life that describe their role as being someone who assists the participant make decisions?

I have not ticked the decision supporter has been chosen by the participant as if it is family there really isn’t a real choice. If another person who is informally connected or a formal supporter there may have been some choice among a number but for the reasons above it will be very difficult for this to be judged by an NDIA staff or partner.

I have not ticked a registered provider as the registration process is not nearly robust enough to ensure the values and actions of an individual staff member are appropriate. However this is not to say that there are individual staff members who do meet all the criteria and can be very effective decisions supports for participants to whom they provide paid support. I have seen this frequently in my decades of involvement with people with disability.

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

The content is the sections above about the wide diversity of characteristics and situations in terms of decision making and how assistance is best provided is also relevant for decisions about NDIS plans. The only difference is that it is necessary for the person with disability and/ or their decision supporters need to be knowledgeable about the complex NDIS plan rules, guidance and the current trends in plan decision making by the NDIA that are often not written down.

Support for Decision Making consultation submission

**Name:** Individual 27 (WA)

**Date and time submitted:** 8/24/2021 11:55:00 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: Yes
* 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

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

See additional comment on attached.

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: No
* NDIA Partners: No
* Advocates: Yes
* Service Providers: No
* Other: No

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

See additional comments attached.

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

See additional comments attached.

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

See additional comments attached.

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

These information sessions need to be undertaken by local and trusted organisations which are well resourced and deliver the information over a long period of time. This will require significant resources and long term investment.

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?**

Hearing the person with disability through their verbal communication and their behaviour. Being very persistent and patient to enable the decision to be enacted.

**What could have been better?**

Part of the delay was to convince the then state appointed Plenary Guardian from the Office of the Public Advocate that this was the will and preference of the person.

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

These information sessions need to be undertaken by local and trusted organisations which are well resourced and deliver the information over a long period of time. This will require significant resources and long term investment.

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

**An intellectual disability:** Yes, Firstly it is important to understand that there is very wide variability in terms of people with an intellectual disability. By definition the disability is present from birth and involves difficulty learning. The development of decision making capability needs to be undertaken using a range of approaches that are skillfully and consistently used throughout the life span in the same way as all life skills are developed for the specific type of intellectual disability

**A disability that impacts how they think, a cognitive impairment:** Yes, Firstly it is important to understand that there is very wide variability in terms of people with cognitive disability. For example the experience of a child with head injury will be very different from someone whose cognitive disability is the result of late stage MS. Specific approaches need to be evidence based and tailored to the individual.

**A psychosocial disability:** Yes, Firstly it is important to understand that there is very wide variability in terms of people with psychosocial disability. The extent of their disability will vary over time as their mental illness is more evident. It is critical that decisions about triggers and strategies are made when the person is most capable for those times when they become unwell. This requires highly skilled support and intervention.

**A disability that impacts their ability to communicate:** Yes, Firstly it is important to understand that there is very wide variability in terms of people with disability that impact their ability to communicate. It is also likely that this will be associated with other descriptors included in this section. eg intellectual disability. There are aids and IT that with careful assessment and implementation can assist but it is essential that there is training for everyone around the person so that the communication aid is used effectively and the decisions communicated are heard and act on.

**From a CALD community:** Yes, Firstly it is important to understand that there is very wide variability in terms of CALD communities. Cultural competence for the specific community is the basic requirement. Then all the variables related to the individual disability need to be taken into account.

**From an Aboriginal or Torres Strait Islander Community:** Yes, Firstly it is important to understand that there is very wide variability in terms of Aboriginal and Torres Strait Islander communities. Cultural competence for the specific community is the basic requirement. Then all the variables related to the individual disability need to be taken into account.

**From the LGBTIQA community:** Yes, Firstly it is important to understand that there is very wide variability in terms of members of the LGBTIQA + community. Specific knowledge related to the community and the individual is important. Then all the variables related to the individual disability need to be taken into account.

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

The definition of Conflict of interest also covers where there is a perceived conflict that needs to acknowledged and mitigated. There are situations where participants with limited or non existent informal networks and a single provider may be at risk however there are also many examples where a staff member who knows the person well over a long period of time is able to assist their will and preference and decision making effectively. I have seen this on many occasions over a long time. There is no one size fits all solution to reducing conflict of interest.

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

The most effective safeguard is a rich network of family, friends, community members and a variety of paid supports . The starting point is to determine the extent of the participants network and for those with none or one in which undue influence appears to be occurring than there should be specific supports included in their plan to build networks. eg Circle of support.

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

The most common scenario is when it is stated that a particular activity is the persons choice. The classic example is watching television all day when there has been no other activities offered or experienced. Therefore decision making needs to be clearly as a result of informed choice.

The other circumstance is when a person with disability may not be adequately supported when making a decision that puts them at severe risk to understand the consequences and the application of appropriate dignity of risk .

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

While the consultation paper and the Decision Making Capability Framework include life stage and children and young people there if no mention in any of the actions about Child Representatives. Like all skills decision making begins at early and continues to develop throughout life. It is important to include families or other representatives in the provision of information, resources, encouragement , promotion etc.

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

Goal 1 - These actions do not recognise and separate decisions happening in daily life and those involved in the NDIS planning and implementation. They are not the same. An operational guidance can only be relevant for NDIA decision making rather than inclusive of day to day decision making in all life areas .

A targeted approach for complex cohorts is a very large and complex undertaking and it is unclear which decision making opportunities are meant.

Development of resources will be of benefit but will be insufficient without delivery through trusted organisations over a long period of time which will require a significant investment of resources.

There will be a need of a significant investment in training for NDIA staff and partners that is sustained over time.

The add on as an Indicator of success a reduction in Nominee appointments needs further consideration. See Goal 4.

Goal 2 - the actions are worthy and ambitious.

Given that the building of capability involves actions in every day life by formal supports involved the provision of a line item support that is fixed and therefore presumably delivered by someone external to the single service provider seems limited in value and rigid in approach to the recognized issue

Goal 3 - Development and publication of best practice and "Guidance " features heavily in the proposed actions. While likely to be somewhat helpful there needs to be significant investment in implementation that will need to be tailored for each of the stakeholders . It is not clear if the proposed NDIS specific training will involve the required depth and long term commitment for the significant change management involved.

Goal 4 - while I fully agree there should be a strengthened decision making support approach to the appointment of Nominees there is a risk of making the process overly bureaucratic . The complexity of the planning process and subsequent processes of implementation and review have made it more difficult for participants who are able to make decisions about their goals, day to day life and services to navigate the system to have their plan work for them and therefore more likely to utilize a Nominee.

The diverse individual and situational characteristics that impact on decision making capability will make it challenging to identify " cohorts with disproportionate nominee appointments.