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

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

1. 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 Karlene 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.