Support for Decision Making consultation submission

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# 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

It is important to structure, and provide scope documents for use, by those roles that assist individuals to make informed decisions. What is their role in this process, and guidance for participants about their experiences with this roles, as a participant of the NDIS. This also aids the development of a consistent standard of behaviour, and role compliance, monitoring of conflicts of interest, unethical practices, at a national standard. It is evidenced within our practice that many roles supporting individual participants, work outside of their scope of practice, remove the rights of other professionals to practice ethically and administer guidance, recommendations and other extremely unethical behaviour. Helping individuals is not going to be one single solutions, it is going to need to be a responsive solution. Additionally oversight, guidance on language, how is this additional work for those assisting to be funded, how will it be recorded for the management of indicators for success?

# Who are the best people to help you (or a person with a disability) to make decisions?

* Family: No
* Friends: No
* Peer Support Networks: No
* Mentors: No
* Coordinators: No
* LAC: No
* NDIA Partners: No
* Advocates: No
* Service Providers: No
* Other: No

# What should they do to help with decision-making?

As an individual participant this will be determined by them, they are the best person in most (exceptions noted) to choose who assists them, and they should be supported to know who can assist them, their role in that assistance and what to do when things go wrong. It is important not to displace the individual within an informed decision making model, which to often occurs in systems (i.e. mental health, primary health MAI insurance, NDIS) and it adds to multidimensional trauma and deteriorating outcomes for individual participants.

# 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

A complex answer, it may not be in the best interest for others to make decisions. They may not have the associated skills for problem solving (reason, judgement, analysis). Perhaps encourage providers and the participant to work in an MDT approach, which could be funded for the individual, at various levels dependent on disability to assist. What is lacking in this NDIA model of care is a cohesive national standard for the teams often revolving around an indidviudal living with disability, to work together. When this is absent, how can informed decisions be managed? In doing so not only is the individual more informed, there is the management of risks associated with poor decision making, risks associated with the current landscape of fragmented care.

# 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 decision will be unique to each participant, it is important not to displace the individual in this process. Roles of the right people should be defined, as mentioned above. In these role descriptions define the limitations and legal responsibilities in the decision making process, to prevent the wrong support occurring and poor outcomes for individual participants. It is evidenced in our practice, that the NDIA review process, disregards informed decisions by clinicians and other professionals, and support coordinators, act unethically as gate keepers, disregarding professionals advice and recommendations which is dangerous, abusive and neglectful at best. A bottom up approach is required. The NDIA must develop a trust in the professionals providing care and support to indivdiual participants and their recommendations and not seek to disregard, diminish or water them down to save money. Individuals quality of life is being modified based on this, with detrimental affect, for them, their families and carers and their communities. It is also leading to discontent within the professional realm for many clinicians, who become burnt out, leave the sector, or refuse care of NDIS participants.

# 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

Their scope of practice, what is expected of them in this process, the level of understanding by the participant about their NDIS supports, plan and services, it is evidenced in our practice, that few understand their plans, services, and what is available. We engaged with many participants to educate them, as their support coordinators have not, about this to remedy their ability to make decisions. Some support coordinators are making decisions for participants without their involvement, this is evidenced in our practice. Those assisting should understand the whole person, their systems, supports and goals. They should also understand that capability and capacity are different for everyone, and what one individual may achieve in 3 months, another may never achieve, making informed decisions in these scenarios is extremely important for these individuals.

# 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?

Supporting the indivdiual to speak with their clinical team, allowing them time to digest information, multiple conversations, exploring all the choices and mapping these out using some mind mapping strategies, supporting the production of communication between service providers, assisting the individual to construct correspondence to ask for more assistance, providing a statement, they could take with them outside of session to sit with their decision and understanding before taking the next steps with certainty.

## What could have been better?

Having assistance to stop a Support Coordinator stepping outside of their scope of practice and interfere in the decision making process, they have no legal right to make decisions for individuals, in our experiences, it is evidenced that there is enormous unethical behaviour in this domain. We report this unethical behaviour and there is often no action, no real outcomes, and in the meantime, bullying occurs within the sector to organisations who do want to practice ethically, we have individuals who are neglected, traumatised, and services are fragmented, care is fragemented.

# 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: Yes
* Guidance Tools: No
* Not Sure: No
* Other: Yes

As a professional I engage with individuals in creating suitable resources, repetitive conversations, seeking external consultation and information outside of our practices with the individual, building their skills for self-advocacy and to trust their own experiences. Using trauma informed principles, empowerment, safety, trust. We also document decisions, extensively, how they may have been discussed, store correspondence and can provide this evidence if it was ever requested. We have developed forms for our Community Support Workers to utilise in their work, especially in vulnerable decision making (i.e. financial) to manage risks. We train and supervise our Community Support Workers extensively.

# Are there different things to consider for people with different disabilities or cultural backgrounds?

**An intellectual disability:** Yes, Their ability to make decisions, as a vulnerable person in doing so. However there is a fine point, on what would be considered, their rights to make decisions and interference from systems, individuals and networks about this that would see removal of their rights to make decisions. It may in this circumstance, support individuals with an intellectual disability, to have an external consultation service to talk about their decisions if they would like.

**A disability that impacts how they think, a cognitive impairment:** Yes, A vulnerable person making decisions, learned behaviour (i.e. compliance) for example, if they are domestic and family violence survivors, where decisions were coercive in nature, and they learned to have no trust in their own experiences. Ensuring the team around them is consulting and sharing information appropriately and individuals are working within their own scopes of practice, and the right to practice to each individuals standards is supported.

**A psychosocial disability:** Yes, A vulnerable person making decisions, learned behaviour (i.e. compliance) for example, if they are domestic and family violence survivors, where decisions were coercive in nature, and they learned to have no trust in their own experiences. Ensuring the team around them is consulting and sharing information appropriately and individuals are working within their own scopes of practice, and the right to practice to each individuals standards is supported.

Psychosocial disability is a broad term, and is inclusive of a range of diagnoses, that have inherent risks for making decisions, consultation and support would need to be considered on a case by case basis, with a whole person, systems approach in any of these scenarios identified by the above question, however moreso within this cohort.

**A disability that impacts their ability to communicate:** Yes, Resources need to be readable, and comprehension ensured. Resources will need to be flexible for individuals with a range of disabilities, to support them to read, digest, engage with curiosity and move towards decision making. Communication is a broad term and there are going to be considerations for each individuals. Perhaps the question is more about, for each issue, is there an opportunity to specify for people living with disability, to know the pro's and cons of making or not making that decision. Resources can engage in a style of problem solving, as opposed to providing a complex resource of all consideration. I may be that there are going to be times, whereby it would be acknowledged that an informed decision is not possible, how is this managed? Documented? Communicated? What are the risks, how does a clinician manage this? What occurs whereby a clinician can see the risk of harm, whereby others are making decisions that are not in the persons best interests, how is this process documented for all the roles, of the professionals within the NDIS process? This is outside of mandatory reporting. Indicators of success, how should, will this be recorded, as indicators of success will be a range of variables, dependent on the decision, professionals assisting, disability and individual.

**From a CALD community:** Yes, Ensuring their community involvement, not token involvement, and moving outside of the typical agencies that lead this space. Many are underfunded and fatigued.

**From an Aboriginal or Torres Strait Islander Community:** Yes, Ensuring their communities involvement, not token involvement, giving opportunities for leadership, increased access to sitting at the table with the decision makers and support engagement in the production of any collateral.

**From the LGBTIQA community:** Yes, Ensuring their communities involvement, not token involvement, giving opportunities for leadership, increased access to sitting at the table with the decision makers and support engagement in the production of any collateral. Young people's involvement and their families.

# How can we help reduce conflict of interest?

Within our practice we have procedures to manage this, however we observe the roles that support the NDIS, Support Coordinator, many are not aware, or do not observe their own conflicts of interest, when interfering in the practice of professionals, not providing information to the NDIS that is providing by professionals, and this represents a significant issue. As some SC's believe they have a right to make decisions outside of the individuals interest and this displaces the individuals and harms them in the process. I have a significant cohort of individuals, whereby this is their experience. And the therapeutic space is deteriorating until such time as this trauma is managed. It stops individuals from finding their agency, they want to withdraw from the scheme, due to the cognitive and emotional affects of having a system that presents a message of choice and control, whereby the individuals choice and control is removed, multidimensional. Where the clinicians, and other professionals choices, are removed multidimensional, fragmented and neglect is the result.

# How can we help reduce undue influence?

When this is reported, take real action. I have evidenced reporting of behaviours outside of the standards of practice as per the NDIA, with no outcomes of problematic behaviour, and there is no real outcome, no real action or disincentive to this behaviour. Not all participants, whom are already traumatised by being displaced in decision making want to participate in the complaints process, however the notion that a participant must give consent, is a decision that requires review. How can a clinician act with integrity and ethical approaches, in reporting behaviour of concern, and I personally would not be vexatious in our claims, when a complaint will only be taken if the individual participant participates, or gives consent? This is unethical and is leading to behaviour of unethical nature continuing to harm individuals.

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

Individuals should not be displaced by any system. They have a right to be as involved, as is considered by a reasonable person, given their circumstances. What language is going to be used consistently to describe how and who assists, and what their roles are? Is there a list for individual participants to check off as they are making a decision that builds their capacity and capability, a problem solving approach for decisions as opposed to information on how to make decisions. (i.e. Did you know that when making a decision about whether you need psychology support you might want to consider A, B, C and here are some important links to find a psychologist, what you need to know before you see them, and what you can do if you are not happy with your treatment, this is what you need to know about how much it costs, and how it will be billed to your plan).

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

Trust that they know their experiences, this is missing. That a person living with a disability, lives with this disability everyday, and they know what assists and what does not. This may not fit in with the medical, clinical or systematic expectations, this should not be devalidated, as this is leading to harm. There is a sub-culture developing within this system, of those individuals who are well supported, those who are not and those that are something else (i.e. being harmed by the system and falling through the gaps, having funding reduced as they have not been able to engage). When an individual is displaced in a system, it leads to inability to make decisions. Ultimate an inability to choose care, inability to access assistance that is appropriate because the individual has determined it is appropriate, that aids their quality of life. When a person is displaced in the system, and their choices devalidated it contributes to ongoing trauma, worsening mental health outcomes, which is linked to deteriorating overall outcomes.

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

There are in existence models for informed decision making. The published guidance, will need to be expanded beyond it's current list, and the domains for specific decisions, should be included in this guidance (i.e. support coordinators, do not make decisions about transition of mental health care and supports or the types of therapeutic supports required by a participant, and they do not disregard clinician decisions, when clinicians choose to transition services for individuals, they do not have any decision making in the treatment, what-so-ever of individuals, outside of their scope of practice, which is to connect individuals to services), this is occurring and it is dangerous behaviour. In one instance, we have evidenced, that a participant could have potentially lost their life, due to how a support coordinator was making decisions of this nature without expertise, documented evidence.