

D21/1418683

9 September 2021

National Disability Insurance Agency (NDIA)

Via: <https://www.ndis.gov.au/community/have-your-say/support-decision-making-consultation>

Dear NDIA

Re: Consultation Paper: Supporting you to make your own decisions

Thank you for the opportunity to provide feedback on the proposed Support for Decision Making policy.

The Disability Council NSW (the 'Council') is a statutory body that provides independent advice to the Minister for Families, Communities and Disability Services on matters that affect people with disability in NSW and their families and carers.

The Council endorses the aims and key principles of the Support for Decision Making policy. Please find below responses to the questions asked in the consultation paper.

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

To help people make decisions for themselves, it is essential that their circumstances and capacity are considered. The type and severity of disability will influence their capacity to make decisions and, in turn, the support required.

To support people with disability to make decisions that are right for them, service providers and other formal and informal decision supporters need to be cognizant of any personal bias that may unduly influence a person's decision making.

The provision of training is essential to help service providers and carers develop the knowledge and skills to support decision making effectively. The training should focus on how best to support decision-making, understand potential bias, and understand potential conflict of interest.

As highlighted in the consultation paper, it is important that a distinction is made between high value (life-changing) decisions and small value (everyday) decisions.

The creation of a series of tailored decision support tools would be beneficial. At the time the NDIS was being introduced, many government and non-government agencies developed tools

that could be leveraged. The Council for Intellectual Disability, for example, completed work on capacity building.

The NSW Department of Communities and Justice has also developed a [Capacity Toolkit](#), which is a guide to assessing a person's capacity to make legal, medical, financial and personal decisions. Please refer to www.justice.nsw.gov.au/diversityservices/ for more information.

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

People with disability should be encouraged to make decisions for themselves. Where help is required, a range of people may be appropriate depending on the individual. They can include both formal and informal supports such as support coordinators, parents, siblings, the person's partner, or enduring guardian.

As outlined above, it is essential that both formal and informal supporters have received training related to decision making. It is equally important that decisions are regularly revisited, particularly at key transition points in a person's life. People change as they grow older, and so do their needs.

Independent, neutral decision supporters can often elicit information that the person with disability may not feel comfortable sharing with a family member or others close to them.

3. What should they do to help with decision making?

It is important that in the first instance, people with disability are asked what they would like to happen. The support needed to assist with decision making will depend on the person's circumstances and capacity to make decisions.

The person assisting with decision making should use a decision support tool rather than just rely on their subjective judgement. This will help to eliminate bias.

It is also important to be mindful of the amount of information and options provided so that the person isn't overwhelmed, causing 'decision paralysis'.

Examples of best practice decision support tools can be found via the Canadian Institute for Health Information, and examples of best practice decision aids can be found via the Ottawa Hospital. Please refer to www.cihi.ca/en/submit-data-and-view-standards/methodologies-and-decision-support-tools and <https://decisionaid.ohri.ca/> for more information.

4. How can they get better at helping?

The need for regular, ongoing, high quality, evidence-based training cannot be overstated. This includes training for service providers, NDIS planners, formal and informal carers, and support workers.

Prior to the rollout of the NDIS, the Council for Intellectual Disability delivered Voice, Choice and Control training, which focused on differentiating between what the person with disability wants versus what the carer wants for them.

To ensure quality control, the NDIA should be monitoring outcomes when someone other than the person with disability is making decisions to ensure there is no bias or conflict of interest.

A community awareness campaign highlighting that supporting people with disability is a community responsibility would also be beneficial.

5. How can we make sure the right people are helping? For example:

- **that they are building the capacity of the person with disability,**
- **that they are considering what the person with disability wants.**

United Nations Convention on the Rights of Persons with Disability (UNCRPD) is a good starting point insofar as it requires people with disability to be the chief decision-makers in their lives. Australia is a signatory to the UNCRPD.

To ensure the right people are assisting in the decision-making process and that the outcome is in the best interest in the participant, the NDIA could evaluate a random sample of decisions.

6. What should decision supporters know about so they can help people with disability make decisions?

Decision supporters need to have knowledge of different disabilities and the potential influence on decision making. They also need to have the necessary skills to support decision making without deciding for the person with disability. It is important that people supporting the decision-making process can recognise their own personal biases.

Positive risk should be encouraged to empower individuals and promote capacity building. Finally, there should not be a time pressure to make decisions.

7. Can you tell us about a time when someone helped you (or a person with disability) to make a big decision? What worked well? What could have been better?

The examples below highlight the importance of providing practical supports, linking people to appropriate organisations and others with shared experiences, and the need to manage the quantity and delivery of information.

The first example relates to a person with an acquired physical disability. In the first instance, practical support was provided in the form of a wheelchair. What proved particularly beneficial was linking him to other people in wheelchairs with a shared experience. The amount of information provided at the time, however, was too much and overwhelming.

A second example highlights the importance of finding the proper organisation for an individual. Linking Aboriginal young people to a disability support service owned by an Aboriginal organisation was very positive. Receiving support from this agency not only enhanced his cultural understanding but also helped him to grow and feel more confident communicating with people.

8. What is the best way to support people with disability to make decisions about their NDIS plan? This includes decisions about using or changing their plan.

It is essential that a series of decision support tools are created, and that training is delivered to both people with disability and the people supporting them. Again, it is imperative that the tools and training are tailored to reflect the different circumstances and capacity of individuals.

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

One size does not fit all. It is essential that training, supports, tools and resources are tailored to the needs of different audiences to ensure they are relevant and culturally appropriate.

10. How can we help reduce conflict of interest?

Training needs to be delivered to help formal and informal carers recognise conflict of interest and the importance of declaring it.

11. How can we help reduce undue influence?

The provision of independent support by people who are not service providers may help to reduce the undue influence. It would be beneficial to randomly select 3-5% of decisions to investigate compliance with best-practice decision making.

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

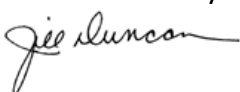
People with disability should be involved in decision making to the maximum extent possible. There is a risk that some service providers may take advantage of the person with disability or their carer. Some carers experience distress when their child has been diagnosed with a disability and are overly influenced by service providers who may have both a conflict of interest and undisclosed (or unrecognised) bias.

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

Establishing support groups so that people with disability can understand the decisions of other participants may assist them in understanding other possible service options. This would also help carers.

Thank you once again for the opportunity to contribute to this important inquiry.

Yours sincerely



Dr Jill Duncan

Deputy Chair, Disability Council NSW
disabilitycouncil@fac.s.nsw.gov.au