

10 September 2021

National Disability Insurance Agency (NDIA)

GPO Box 700

CANBERRA ACT 2601

Submitted via survey to the NDIA: [Online survey](https://myform.apps.ndia.gov.au/?src=https://forms.apps.ndia.gov.au/jpgbthlbzknpuvv/sfdm&org=ndis&theme=ndis)

Dear Sir/Madam

**Australian Psychological Society response to the**

**NDIS Consultation Paper: Supporting you to make your own decisions.**

The Australian Psychological Society (APS) welcomes the opportunity to provide a submission in response to the proposed NDIS support for decision making policy and associated principles, goals and decision making capability framework outlined in the Consultation Paper: Supporting you to make your own decisions and the Companion Paper: Supporting you to make your own decisions.

The APS is the peak professional body for psychology in Australia, with more than 27,000 members nationally, many of whom work in the disability sector and with NDIS participants. We are responsible for promoting excellence and ethical practice in the science, education and practice of psychology as the key discipline for reducing the burden of mental ill-health and increasing the wellbeing of all Australians.

The APS has a long history of working with the Government and other agencies to establish standards to ensure the quality and safety of mental health care. We are keen to assist and partner with the NDIA to support policies and guidelines that ensure NDIS participants can receive equitable, accessible and effective support for decision making that enables them to live active and fulfilling lives.

The submission that follows is based on feedback sought from members and current evidenced-based practice about decision making support. We note that the questions contained in the Consultation Paper are primarily structured to capture the voice of NDIS participants and supporters. The APS appreciates the importance of this whilst also welcoming the opportunity to provide a professional perspective about supported decision making (SDM) and has structured our response accordingly.

**1. Proposed decision-making capability policy and framework – design and implementation considerations**

Within the Consultation Paper, the NDIS presents a Decision Making Capability Framework (the Framework, pp. 9-16) that comprises factors that influence a person's decision making capability. These factors include the decision Circumstance (Capacity, Life Stage, Options), Supporters (Informal, Formal, None) and Decision characteristics (Type, Level, Impact).

The APS commends the approach of the NDIA to communicate the Framework in an accessible way for NDIS participants and their supporters by using a diagram with minimal/plain language and accompanied by more detailed text explanations. While the Circumstance and Supports elements of the Framework diagram sufficiently capture the intent described in the detailed text, the Decision element is less clear. For example, Decision 'Impact (Significant, Important, Minor) needs to be more clearly differentiated from Decision 'Type (Life changing, Lifestyle, Every day)' and better reflect the personal value of decisions as described in the detailed text. An alternative might be to replace decision 'Impact' with 'Value' or 'Importance' in the Framework diagram and remove the smaller text that confuses type and impact.

The Framework diagram elements are well-explained in the accompanying text, except for the category

"Supporters: None." This oversight means there are insufficient details and expectations provided in the proposed policy for people with disabilities who are identified as having no informal or formal decision supporters and are especially vulnerable. The APS would be pleased to partner with the NDIA to facilitate the development of necessary documentation for NDIS policy, procedures, and guidelines for individuals without support, to enable them to communicate their will and preferences to NDIS staff, partners and service providers.

A substantive concern relates to SDM Capacity considerations in the detailed text accompanying the Framework diagram. A decision making continuum is presented to assist with understanding decision-making capacity (Consultation Paper, p. 11). The continuum ranges from low to high autonomy, and in the accompanying text it is appropriately noted that autonomy is influenced by many factors and can fluctuate from time to time. This needs to be made more explicit in any visual representation of the continuum. Of additional concern, people with high autonomy are positioned in the Consultation Paper as capable of making, communicating and enacting all their own decisions based on information and knowledge of the options. Decision making, however, is not a solely cognitive exercise and may be associated with considerable emotional and existential turmoil related to impacts on others and challenges to values, identity and purpose1. Across the decision-making continuum, some individuals with disabilities, including those at the highly autonomous end of the scale, may require expert psychological support to adequately navigate decisions that are not easily resolved with a reasoned approach of weighing the pros and cons. People with cognitive disabilities and complex needs, who have limited decision making experience and difficulty securing supporters, may also benefit from expert psychological support to integrate decision making and engage ongoing supports2.

With expertise in supporting individual and group decision making, psychologists are uniquely placed to support the decision making of people with disabilities across the autonomy continuum in the following ways:

* Psychologists have a commitment to providing evidence-based psychological support and intervention to assist individuals with disabilities to articulate and make decisions that matter to them.
* Psychologists have the expertise to comprehensively assess the full range of often changing individual and contextual factors that may impact a person's capability to make decisions.
* Psychologists are competent to work with individuals with a disability who are chronically disempowered or may experience, or be at risk of, undue influence, coercion, abuse, or neglect. Psychologists can provide trauma-informed, recovery-oriented, evidence-based, best practice approaches to SDM with NDIS participants.
* Psychologists have expertise in consultation and psychoeducation to support the SDM process for people with a disability and their informal and decision support networks in ways that will increase consistency and the likelihood that an individual's will and preferences remain central.
* Psychologists are competent in identifying organisational factors that may present as barriers to people with disabilities being included in decisions about their lives.
* Psychologists are experts in implementation science, evaluation and system-level improvements. They can identify what data to collect and analyse to determine the success of individual supports and systemic policy and guidelines.

Ongoing concerns currently exist about the quality of the plans developed for NDIS participants and the deprofessionalisation of critical roles. Thus, the APS recommends that the policy, implementation plan and guidelines for SDM acknowledge the significance of psychological assistance and interventions (provided by psychologists) as a key decision making support. Psychological assistance needs to be accessible to NDIS participants as an integral part of their NDIS plans.

**2. Proposed next steps (Appendix C)**

* The NDIS Consultation Paper, Appendix C, presents proposed actions to implement and evaluate the policy framework. The APS would like to partner with the NDIA on the proposed decision making operational guidelines, particularly as they pertain to the identified 'complex cohort' that includes participants with intellectual disability, cognitive impairment and psychosocial disability (p. 23). APS consultation would also benefit the development of best practice NDIS resources that describe SDM as they pertain to these cohorts.
* The NDIS Consultation Paper, Appendix C, proposes using 'business intelligence' to predict when support for decision making is potentially needed. There will be a specific focus on life stage transitions 'through data driven system alerts" (p. 24). The APS would like to partner with the NDIA to embed person-centred approaches as an alternative to potential over-reliance on 'typical' life stage transitions that may not map onto the experience of individuals who have complexities in the context of intellectual disability, cognitive impairment, and/or psychosocial disability.
* The NDIS Consultation Paper, Appendix C, proposes that a formal process will be introduced 'to identify a participant's decision making capacity that is aligned to the policy framework. We will do this at the beginning of their NDIS journey' (p. 25). The proposed action risks positioning decision making status as a static variable (rather than decision specific and variable across time). It could unnecessarily limit expectations for NDIS participants about their participation and engagement in the decision making processes. The APS would be pleased to contribute our expertise to developing this formal process and the proposed review of capability assessments to mitigate these risks.

Thank you again for the opportunity to respond to the NDIS Consultation Paper: Supporting you to make your own decisions. If any further information is required from the APS I would be happy to be contacted through my office on (03) 8662 3300 or by email at z.burgess@psychology.org.au

Kind regards

**Dr Zena Burgess, FAPS FAICD** Chief Executive Officer

References

* 1. McCue, J. (2020, September). Decisions, decisions: Psychologists helping with life choices. *InPsych*, *42*(4). [https://www.psychology.org.au/for-members/publications/inpsych/2020/Aug-Sept-Issue4/Decisions,-decisions](https://www.psychology.org.au/for-members/publications/inpsych/2020/Aug-Sept-Issue-4/Decisions%2C-decisions)

* 1. Bigby, C., Douglas, J., Carney, T., Then, S., Wiesel, I., & Smith, E. (2017). Delivering decision making support to people with cognitive disability—What has been learned from pilot programs in Australia from 2010 to 2015. *Australian Journal of Social Issues*, *52*(3), 222–240. <https://doi.org/10.1002/ajs4.19>

**Support for Decision Making consultation submission**

**Name:** Australian Psychological Society (National)

**Date and time submitted:** 9/9/2021 2:30:00 PM

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

* Resources: No
* Information: No
* Decision Guides: No
* Having a person help: No
* Other: No

# **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?**

No answer recorded

# **How can they get better at helping?**

* Getting to know the participant well: No
* Doing some training on decision support: No
* By having resources and information about providing decision support: No
* Other: No

# **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: No

# **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: No

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

No answer recorded

## **What worked well?**

No answer recorded

## **What could have been better?**

No answer recorded

# **What is the best way to support people with disability to make decisions about their NDIS plan?**

* Practice: No
* Peer Support Networks: No
* Information and Resources: No
* Guidance Tools: No
* Not Sure: No
* Other: No

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

**An intellectual disability:** No

**A disability that impacts how they think, a cognitive impairment:** No

**A psychosocial disability:** No

**A disability that impacts their ability to communicate:** No

**From a CALD community:** No

**From an Aboriginal or Torres Strait Islander Community:** No

**From the LGBTIQA community:** No

# **How can we help reduce conflict of interest?**

No response recorded

# **How can we help reduce undue influence?**

No response recorded

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

No response recorded

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

No response recorded

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

No response recorded