



**Submission to the National Disability Insurance
Agency's *Support for Decision Making*
consultation**

10 September 2021

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Our vision is an Australia that values and supports the contribution that carers make both to the people they care for and to the community as a whole.

We believe all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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Carers Australia acknowledges Aboriginal and Torres Strait Islander peoples and communities as the traditional custodians of the land. Carers Australia is based on Ngunnawal and Ngambri country, and pays respect to and celebrates elders past, present, and emerging. As an inclusive organisation, Carers Australia also celebrates people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.

Introduction

This submission is made in response to the consultation paper [Supporting you to make your own decisions](#) and its companion paper. The submission has been informed by the network of state and territory Carer organisations. Carers Australia has also consulted with [Inclusion Australia](#), as the peak body for a large proportion of the 60% of “adult NDIS participants who have a disability that may affect the way they think.”¹

Carers Australia welcomes the opportunity to engage with and provide comments on these papers, and wants to work with the National Disability Insurance Agency (NDIA), other relevant area of government, people with disability, disability representative organisations (DROs), disabled peoples organisations (DPOs), and advocates to improve the National Disability Insurance Scheme (NDIS) for participants, carers, families and the community.

Carers Australia notes these consultation papers have been developed by the NDIA following the 2019 Independent Review of the NDIS Act 2013 (the “Tune Review”). The Department of Social Services describes the current suite of reforms activities as seeking to “improve the NDIS” and “make the NDIS fairer, with better information for decision making, at less cost for participants and those applying to become participants.”²

At the time of writing this submission, in response to widespread messages of concern from participants, carers, advocates, and peak bodies across the sector, Minister for the NDIS, Senator the Hon Linda Reynolds CSC announced independent assessments will not proceed.³ The advice and recommendations provided in this submission may need to be revisited once the new person-centred model is developed and implemented.

Supported Decision Making policy considerations

Carers Australia affirms the importance of rooting all frameworks surrounding capacity, consent, and decision-making in the [United Nations Convention on the Rights of Persons with Disability](#) (CRPD). Carers Australia believes people with disability have the right to make decisions.

The NDIA has outlined a range of challenges and problems currently experienced by participants, carers, families and advocates relating to consent, capacity, and decision-making. While the paper captures most of the key issues, Carers Australia is concerned the current policy solutions will insufficiently address these, and may instead create further challenges.

Definitions and language

Both the papers and the NDIS website define ‘supported decision making’ as the term describing the process, and differentiates ‘support for decision making’ as the term which “refers to a range of: informal and formal, paid or unpaid supports, or resources that are available to a person to help them to make a decision.”⁴ This delineation is unnecessarily confusing for participants, carers, and the community.

¹ National Disability Insurance Scheme (2021). *Supporting you to make your own decisions – consultation paper*. Accessed 19 August 2021 <<https://www.ndis.gov.au/media/3231/download?attachment>>, p5.

² Department of Social Services (2020). *NDIS Reforms – Information Paper*. Accessed 19 August 2021 <<https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability-national-disability-insurance-scheme-2019-review-of-the-ndis-act-and-the-new-ndis-participant-service-guarantee/ndis-reforms-information-paper>>.

³ National Disability Insurance Scheme (2021). *Independent assessments proposal*. Accessed 19 August 2021 <<https://www.ndis.gov.au/about-us/history-ndis/independent-assessments-proposal>>.

⁴ National Disability Insurance Scheme (2021). *Supporting you to make your own decisions – consultation paper*. Accessed 19 August 2021 <<https://www.ndis.gov.au/media/3231/download?attachment>>, p30.

Recommendation: Use ‘supported decision making’ as the term which applies to both the process, and resources and tools.

The consultation paper uses the words ‘capacity’ and ‘capability’ interchangeably, which obscures meaning in some parts, and periodically confuses the regular and legal definitions of both words. The confusion between the two terms is pronounced in the paper’s Decision Making Continuum.

Recommendation: The NDIA clearly defines both ‘capacity’ and ‘capability’ to align with sector understanding and usage. Going forward, use the appropriate term in the Framework and its associated information.

Key principles

While the NDIA’s proposed principles are not inherently incorrect, Carers Australia endorses Inclusion Australia’s position that they are unnecessary given the Australian Law Reform Commission’s ‘National Decision-Making principles’ provided in their *Equality, Capacity and Disability in Commonwealth Laws* report.⁵ These principles better protect participants, their carers, and the community, as they go above and beyond the NDIA’s proposed principles to provide guidance about respect, communication, will and preference, rights, and safeguards.

Recommendation: The NDIA should adopt the ALRC’s ‘National Decision-Making principles’ provided in their *Equality, Capacity and Disability in Commonwealth Laws* report.

Empowering culturally diverse participants, carers and other supports

The NDIA, NDIS frontline staff, and NDIS providers must recognise, respect, and respond to the varying approaches to decision making across a range of cultures. Participants from a culturally and/or linguistically diverse background may present with help-seeking behavior which is different to other participants. Participants may feel shame or guilt about requiring support, relying on others, or asking for help.

While this consultation focuses on the experience of participants, carers and their other supports, the policy implementation must be delivered along with guidance for NDIS frontline staff. Working with participants, carers and NDIS frontline staff, the forthcoming operational plan could include case studies and examples of potential supported decision makers could aid NDIS staff to understand common relationship dynamics and how they differ across cultural settings. This could help shift away from the current system where service providers or support workers often are appointed as Nominees.

Recommendation: The NDIA should work with multicultural and Aboriginal and Torres Strait Islander participants, carers and community leaders to ensure the supported decision making framework is culturally appropriate.

Decision Making Capability Framework

While the Decision Making Capability Framework (‘the Framework’) captures most aspects and factors surrounding the issue or situation the individual is required to make a decision, but does not articulate how these factors relate and interact with a participant’s decision-making journey. It is unclear how they will be enshrined as core considerations which input into a participant’s decision-making journey.

Consent

The supported decision making policy proposed in the consultation paper assumes all participants will consent to supported decision making – this is not the case. A participant

⁵ Australian Law Reform Council (2014). *Equality, Capacity and Disability in Commonwealth Laws – Final Report*. Accessed 19 August 2021 < https://www.alrc.gov.au/wp-content/uploads/2019/08/alrc_124_whole_pdf_file.pdf>.

may choose not to consent to participating in a supported decision making process, and the NDIA must consider an alternate pathway to ensure non-consenting, legally capable participants are still adequately supported to make their own decisions.

Additionally, some participants who wish to consent but communicate using aids are locked out in the NDIA's definition of consent as "either verbally or in writing." Noting consent laws differ by jurisdiction, the NDIA should adopt the language used by the Australian Commission on Safety and Quality in Health Care, which sets out the three types of consent as "verbally, written, or implied."⁶

Recommendation: *The NDIA should further consider and expressly consult on the complexities of consent, and the nuances of each jurisdiction before developing its "operational framework for Consent and Informed Decision Making."*⁷

Implementation considerations

As the Framework recognises, participants must be at the centre of the decision making process for any decisions which will impact them and their life.

To better support carers who support participants to make their own decisions, the NDIA must consider a range of issues when developing the operational guidelines. These include:

- working with carers to ensure both the participant and the carer are empowered to keep the participant's choices at the forefront of all communication with the NDIA,
- providing adequate information, resources and training for carers to understand supported decision making processes and their potential role,
- clarifying who has the accountability for ensuring both the participant and their carer(s) understand of the responsibilities associated with being an informal or formal supported decision maker,
- ensuring supported decision makers understand the options available and have all the relevant information to support the individual to contemplate these options to make an informed decision, and
- providing training to supported decision makers to build their own decision-making capability and skills which aid supported decision making processes (e.g. active listening, understanding the participant's communication style and amplifying their opinions, understanding limitations of own knowledge including when to seek expert advice etc.)

Safeguards from undue influence and exploitation

If the participant does not have, or chooses not to include, an appropriate carer, family or friends to support them to make decisions, the NDIA must offer access to an individual disability advocate. The NDIA should provide clear guidance to participants about the potential risks associated with using a supported decision maker who might financially benefit from the participants decisions. The NDIA must formally recognise service providers have an inherently vested interest in the decision made by participants, and build in safeguards to ensure providers or NDIS staff are not regarded as the first point of call for supported decision making roles.

While a participant may choose to be supported in their decision-making by someone who could benefit from their decisions, any paid decision makers who stand to benefit from a participant's decision must expressly acknowledge and mitigate this conflict of

⁶ Australian Commission on Safety and Quality in Health Care (2020). *Informed consent – fact sheet*. Accessed 19 August 2021 <https://www.safetyandquality.gov.au/sites/default/files/2020-09/sq20-030_-_fact_sheet_-_informed_consent_-_nsqhs-8.9a.pdf>, p1.

⁷ National Disability Insurance Scheme (2021). *Supporting you to make your own decisions – consultation paper*. Accessed 19 August 2021 <<https://www.ndis.gov.au/media/3231/download?attachment>>, p26.

interest. A common example which has been provided to Carers Australia is where a support coordinator links the participant into other services, such as financial management, provided by their organisation without providing participants with alternative organisations and options.

This area is currently unregulated with little oversight from the NDIA; many participants and their carers are not aware of the full breadth of their available choices. At a minimum, the NDIA must implement market regulation tools to ensure participants and their informal supported decision makers are aware of and understand who may financially benefit from certain decisions. Better safeguarding could also be implemented through a change to the NDIS CRM where a supported decision makers' declared interests are recorded. This would also provide the NDIA with opportunity to collect data on who is involved in decisions and who stands to financially benefit from certain outcomes. Finally, the NDIA must provide a confidential channel for participants, carers and the community to whistleblow instances of suspected undue influence and/or exploitation. Complaints and tip-offs must be investigated in a prompt manner, as current wait times for matters referred to the NDIS Commission can be months or years long.

Recommendation: *The NDIA should implement better safeguarding mechanisms to minimise risk of participants and carers being exploited by other parties in the supported decision making process.*

Additionally, any supported decision maker must be competent in engaging with participants using a variety of communication methods. Non-verbal participants can often communicate using existing devices and methods developed with their allied health professionals, family and carers, and support staff. NDIS planners must also be adequately trained to be able to recognise when including the participant is not being included to the full extent of their communication capability.

Goals

Appendix C of the consultation paper sets out draft actions and indicators of success under each of the four goals the policy aims to achieve.

Carers Australia supports in principle most of the suggested actions. The NDIA is encouraged to work more closely with carers and their representatives to ensure the actions and success indicators support both participants and carers. The following paragraph raises issues which the NDIA should consider and resolve through co-designing the implementation plan with participants and carers.

Goal 1: Increase opportunity for participants

- Where carers are not provided adequate resources, information and training about best-practice supported decision-making, they will not be able to provide the participant the full range of supports expected from supported decision makers
- If a situation arises where a carer is not included* in decision-making processes, this can negatively impact their ability to provide care related to that decision as they do not have the full context and/or the factors influencing the decision.

Goal 2: Support development of participant capability

- If carers are not included* in the formal process identifying a participant's capacity, their capacity may be judged inaccurately if the assessor does not understand the participant's communication style. Participants and carers must

* In these situations, the carer has not been excluded at the request of the participant, but rather due to other circumstances and external factors.

be involved in the co-design of the formal process, and the NDIA must iterate any process as feedback is received.

Goal 3: Build capacity of decision supports

- Carers must be involved in the design of the operational framework for Consent and Informed Decision Making.
- The current NDIS forms do not adequately delineate what sorts of decisions a participant can make with or without a supported decision maker. Participants, carers, NDIS staff and providers would benefit from clarifying this.
- When publishing guidance and resources, the NDIA should work with community leaders and organisations to widely spread trustworthy information. All community members can benefit from better understanding of best-practice supported decision making processes.

Goal 4: Strengthen support for decision making approach – Nominees

- Carers are concerned the NDIA has listed an indicator of success as a reduction in Nominee appointments, which will be achieved through cutting out unpaid Nominees such as carers.
- If the review of Nominees is triggered by a change of life stages or plan review is not conducted without the right support and education for carers, this may well be quite stressful to both the participant and carer.

Conclusion

Establishing evidence-based, community-approved processes which enable participants to make supported decisions is critical to uphold the human rights of people with disability, and to provide the 'choice and control' promised to participants by the NDIS.

In finalising the Framework, Implementation Plan and Operational Guidelines, the NDIA must work closely with participants, carers, families, friends and other unpaid supports (both informal and Nominees) to ensure the policies and guidelines both align best practice, and are practically applicable and tailorable to real life.