

Submission –
National Disability Insurance Agency
Support for Decision Making Consultation



Queenslanders with Disability Network

Nothing About Us Without Us

24 September 2021

About Queenslanders with Disability Network (QDN)

Queenslanders with Disability Network (QDN) is an organisation of, for, and with people with disability. The organisation's motto is "nothing about us without us". QDN operates a state-wide network of over 2,000 members and supporters who provide information, feedback, and views from a consumer perspective to inform systemic disability policy and disability advocacy. This submission is informed by the lived experience of our members and supporters.

Introduction

QDN welcomes the opportunity to make a submission to the National Disability Insurance Agency (NDIA) Support for Decision Making consultation.

QDN supports the NDIA's intention to make the NDIS simpler, more consistent, flexible, and easier to use for all Australians, supporting and enabling people with disability to have more choice and control over their lives.

QDN agrees that support for decision making will become even more important as the NDIA focuses more on flexibility and choice and control and that the right information, resources, and support are necessary to help people with disability make decisions throughout their NDIS journey. QDN agrees that this is particularly important for participants with complex needs including those with significant cognitive impairment.

QDN urges the NDIA to ensure that decision-making capacity is always assumed, and that the NDIA does not assume authority over deciding a person's capacity; and that the operationalisation of the framework is well-resourced, rights-focused, and person-centred and aligned with the national frameworks instruments for supported decision making.

This submission outlines key messages and considerations that we believe are needed for successful translation from proposal to policy to implementation and impact. These include:

- Assumption of capacity
- Complex needs
- Strengthening the ecosystem of support
- Outcomes measurement
- Investment
- Language
- Cultural Considerations

Recommendations

QDN recommends that:

- The NDIA's starting point for this policy is the assumption of decision-making capacity for every person, and that the first step in the process should be discovery of people's preferred ways of being supported to make decisions.
- The NDIA identifies, supports, and funds participants with a need for specialist decision-making support from trained, skilful, independent, professional advocates.
- Informal supports for decision-making are recognised as the preferred vehicle to meet a person's decision-making needs.
- The NDIA recognises and resources the continued development of peer support networks as a key mechanism for providing peer capacity building around informed decision making.
- The appointment of nominees is only considered when all other avenues for support for decision-making are exhausted.
- Nominees have access to formal training and are monitored and their appointment regularly reviewed.
- Appointment of nominees is a process separated from the planning process and conducted independently of any potential nominee.
- A concerns/complaints process specific to nominees be developed and implemented.
- Paid service providers, including support coordinators should not be appointed as nominees due to the inherent conflict of interest.
- NDIA staff receive extensive training to improve their competency in engaging with people with disability around decision-making needs and that NDIA processes support sufficient time to engage effectively with participants.
- Service providers be required to improve and demonstrate their support for decision-making policies, procedures and practices through registration and audit processes.
- All aspects of the development and implementation of the policy be adequately funded by the NDIA and that decision-making supports in the NDIS Price Guide be more appropriately costed.
- The language of the policy be revised to better reflect a human rights-based and person-centred approach.
- Outcomes measures are co-designed with people with disability to be robust, appropriate, and nuanced enough to capture a range of experiences.
- That people with disability from a range of diverse cultures be engaged in co-design of communications and policy that is sensitive to difference and underpinned by international human rights principles.

QDN's feedback to the Supported Decision Making Discussion Paper

Assumption of Capacity

Article 12 of the Convention on the Rights of Persons with Disabilities (UNCRPD) enshrines people's rights to equal recognition before the law, to the assumption of capacity and to have the supports they need to make decisions. The proposed policy and framework need to begin with this assumption and be reflective of the right to decision making. A contradiction to this in the proposed policy is to 'introduce a formal process to identify a participant's decision-making capacity', which does not start from the premise of assumption and is in direct contravention of the CRPD. Capacity must not be assessed simply to meet the needs of the NDIA. Capacity must only ever be assessed when there is reason to suspect impaired capacity, there is a need for a decision, and the appointment of a decision-maker is required to protect the person's interests. The Australian Human Rights Commission states that assessing capacity should not be the starting point, rather that efforts should focus on assessing the level of support that is needed to fulfil a person's right to make decisions. The current proposed process also ignores the nuanced understanding of decision-making capacity that notes that it takes place in a complex matrix of social and environmental factors and should be decision, circumstance, and time specific. Decision-support needs, rather than establishing capacity, should be the focus.

Furthermore, there are inherent conflicts of interest that arise if the assessment of capacity is undertaken by the Agency, if indeed that capacity assessment is required is also problematic. The Agency is an Insurance Agency with interests that at times may conflict with the interests of the participant. Any capacity assessment that is indicated and necessary should be undertaken by appropriate trained, independent agents.

Complex Needs

The consultation paper recognises that supports for decision-making are found in multiple areas of a person's life - in connection with family, peers, friends, workers, and agencies and in information and decision-making resources – and that NDIA participants would benefit from more supports being made available to them.

However, there is an underlying assumption that this range of supports for decision-making, if simply increased, will meet the needs of all NDIS participants. Some participants are particularly vulnerable, whether it be because of complex communication needs, cognitive issues that inhibit comprehension, lack of informal or formal supports that have sufficient training and understanding of the person, or many other potential complexities and challenges. The supports for decision-making available to them will likely be insufficient to meet these complex needs, not only in quantity but also in skilfulness. The NDIA must find a way to identify, support and fund these participants for specialist decision-making support from independent,

professional advocates who are trained and skilful in working with people to understand will and preferences and to maximise autonomy.

Strengthening the ecosystem of supports

Awareness, knowledge, and skill in the provision of support for decision-making is lacking across the ecosystem of supports that surround NDIS participants. Participants themselves, as well as planners, LACs, family, friends, workers, and service providers may not be aware of or understand the risks of conflicts of interest and undue influence and the contravention of the human rights of a person and negative impact on their life that this may have.

The review of nominee arrangements is welcome. Nominees have duties under the NDIS Act to ascertain the wishes of the participant and act to promote their wellbeing. They also have a duty to develop the capacity of the participant to make decisions – effectively to act to reduce the necessity of their role. How much nominees are aware, capable, or willing to carry out these duties is unknown. Appointment as a nominee is, as the proposal recognises, a first resort rather than a last resort. Monitoring does not take place and there is no mechanism for a participant to make known a complaint or concern about the nominee. Training and support in best practice support for decision-making is not readily available or resourced.

The Discussion paper outlines action to “... *keep encouraging substitute decision makers to involve you in decisions about you and help you to practice your decision making. We will also try to influence substitute decision authorities to help their staff to do this too.*”¹ This focus on substitute decision makers is reinforcing what is currently in place and the NDIA as an Agency does not have any powers to influence substitute decision making authorities to do this.

Informal decision-making supports are natural parts of people’s lives, less intrusive than the appointment of substitute decision-makers and should be encouraged and supported. However, it is recognised that where there are potential risks of exploitation, safeguards need to be in place for individuals. Training and education by the NDIA or another appropriate agency for all informal supporters should be offered to individuals, as identified by the participant, to promote their development as decision-making supporters who will in turn promote the development of participants regarding their own decision-making.

Systemically, the ongoing development of peer support networks through trusted organisations in all jurisdictions needs to be continued and part of the strategic investment of ILC funding. Peers provide a unique avenue for supportive, disinterested (in the sense of generally lacking conflicts of interest), effective support for building capacity of each other in decision-making. The growing capacity, skill,

¹ National Disability Insurance Scheme (2021) [Consultation Paper: Supporting you to make your own decisions](#). National Disability Insurance Agency. p. 15.

effectiveness, and profile of peer networks is invaluable and worthy of continued support, recognition, promotion, and investment.

Appointment of nominees should be a last resort and only made for people without informal supports after extensive engagement with independent decision-support advocates. Nominees should not be paid providers. Nominee appointments should be made independently of planning or plan review meetings and participants given all the information they need about the nomination process and duties and the opportunity to make their will and preferences known regarding nominees free of the potential nominee's presence. Nominees need to receive training in best practice in supported decision-making and a nominee monitoring, review, and complaints process should be implemented that is centred on meaningful engagement with the participant, again, free of the nominee's presence.

Training for Agency staff in effective engagement with people with disability is critical to implementation of the above measures. Agency staff will not have a strong relationship with participants and may know very little about their needs or circumstances, so training in effective communication, the social model of disability, human rights, and decision-making support as well as sufficient time and space (and supporting Agency processes and procedures) for effective engagement are essential.

Service providers will also need to look at how they approach and support workforce development change or bolster their approach. Training for staff and changes to organisational policies and procedures that reflect best practice in support for decision-making will be essential. The NDIS Quality and Safeguards Commission has a clear role here in requiring providers, through registration and audit processes, to meet the Commission's own Practice Standard around 'active decision making and individual choice...support' for participants (as recommended by the Independent Advisory Committee).

The NDIS Quality and Safeguards Commission's interactions with guardianship bodies and legislation in various jurisdictions also needs to be considered, including the role of the Commission in ensuring active decision-making support for people who have formally appointed guardians and application of the Practice Standards. Importantly, even where a substitute decision-maker has been appointed, the assumption of capacity for specific decisions needs to be applied, and that decision-making happens in context and is decision and time specific. Consideration also needs to be given to how can people who have formal guardians appointed still have agency and support in making decisions about their lives, and their development as decision-makers valued.

Investment

Resourcing this strengthening of the ecosystem of supports will be critical. Individual funding in plans for independent decision-making advocates where needed, funding for capacity building activities for participants and informal supporters, ongoing

funding for and expansion of current decision-making pilots and peer support development and activities, funded formal training for nominees, and funding for NDIA internal training and resources for supporting participants in decision-making must all be considered essential in implementation.

As also recommended by the Independent Advisory Committee, a review of the NDIA Price Catalogue item *Assistance with decision making, daily planning and budgeting* in the domain of Improved Daily Living is needed as it is currently priced below the level of basic support work. It is important to recognise the skills, competency and workforce required to deliver this kind of support requires specialist training and practice and should be priced above, not below, the level of support work.

Language

Language matters – it shapes attitudes and behaviour and has a profound effect on how a message is received and the impact it has on people’s lives. It is important that the language used to describe this policy is empowering, person-centred and describes adequately the shift from paternalism.

The naming of the proposed framework as a ‘Capability Framework’ is uncomfortably close to ‘Capacity Framework’. The distinction between the terms may not be readily apparent to people without specialist knowledge, or the casual observer, which description likely applies to many NDIS participants who will be directly affected by the Framework’s implementation. The language of capability may be confused or conflated with questioning of capacity, which, as already stated, contravenes the right to equality before the law and assumption of capacity as a starting point. Preferable terms might be decision-making needs or preferences.

The proposed policy states that ‘in order to implement our policy we have to have a good understanding of the decision you need to make, your ability to make those decisions and what support you need to make them’. This language could imply that the Agency decides capacity rather than assumes it, and that the NDIA has a right to access to information about a person’s life that may not reflect the person’s will or preference about sharing that information. It is important that the language used reflect this process and underlying assumptions.

The proposal also speaks to using ‘business intelligence’ and ‘data driven system alerts’ to predict when support for decision-making may be needed. A supported decision-making approach needs to be embedded across all processes and in all interactions with participants, not only at ‘data points’ of specific age boundaries or transition points. Adopting the language of technology to respond to human rights issues is problematic, and we urge the NDIA to consider how to develop a policy that is broader and deeper in its application and not isolated to key points determined by algorithms.

Outcomes Measurement

QDN supports indicators of success being developed as part of a participatory process, with people with disability and families co-designing proposed indicators of success. Additionally, formats used to gather feedback need to be user-friendly and targeted to the diverse support and communication and needs of participants.

Feedback reinforces those listed in Appendix C need further rigour and detail. Currently, the key quantifiable indicator is a reduction in the number of nominees attached to plans and it is important that this is not seen as a stand-alone, key measurement of success. In fact, it may reflect a worst-case scenario, and simply demonstrate that some people are now without any trusted support for decision-making. Even in a best-case scenario QDN contends it would not show any nuanced capture of improvements in accessible, skilled and effective support for decision-making (which should occur even when a nominee is appointed).

Feedback to QDN further indicates this area requires attention to Key Performance Indicators around participant satisfaction to gather more nuanced information to inform the agency and future initiatives, both at a senior manager and front-line level of work, and assessed by independent agencies, preferably led by people with disability.

Cultural Considerations

Although recognised in the paper, there is little detail around ways that people from Culturally and Linguistically Diverse Backgrounds will be supported to explore and enact decision making in a culturally sensitive way.

QDN recommends a careful approach that does not unintentionally impose the broader community's dominant cultural paradigm on different ethnic or family cultures. Respect for, and account of difference is necessary. This can be achieved through communication and co-design with different cultural groups as the underpinning framework.

Conclusion

QDN commends the NDIA on its efforts to improve supports for decision-making for participants in the NDIS and appreciates the opportunity to make a submission on this important topic. QDN also recommends further refinement of the proposed policy and framework to better reflect a human rights and person centred approach.