

Supporting you to make your own decisions

Submission by
Queensland Advocacy Incorporated
&
Leadership Plus

National Disability Insurance Agency

September 2021

About Queensland Advocacy Incorporated

Queensland Advocacy Incorporated (**QAI**) is an independent, community-based advocacy organisation and community legal service that provides individual and systems advocacy for people with disability. Our mission is to advocate for the protection and advancement of the fundamental needs, rights and lives of the most vulnerable people with disability in Queensland. QAI's board is comprised of a majority of persons with disability, whose wisdom and lived experience of disability is our foundation and guide.

QAI has been engaged in systems advocacy for over thirty years, advocating for change through campaigns directed at attitudinal, law and policy reform. QAI has also supported the development of a range of advocacy initiatives in this state. For over a decade, QAI has provided highly in-demand individual advocacy services. These services are currently provided through our three advocacy practices: the Human Rights Advocacy Practice (which provides legal advocacy in the areas of guardianship and administration, disability discrimination and human rights law, non-legal advocacy support with the Disability Royal Commission, the justice interface and education, and social work services); the Mental Health Advocacy Practice (which supports people receiving involuntary treatment for mental illness); and the NDIS Advocacy Practice (which provides support for people challenging decisions of the National Disability Insurance Agency and decision support to access the NDIS). Our individual advocacy experience informs our understanding and prioritisation of systemic advocacy issues.

About Leadership Plus

Leadership Plus are advocates and decision supporters working closely with people living with complex disabilities in Victoria. We advocate for nearly 300 people each year, with a particular focus on those living with cognitive disability. Over 60% of our work now concerns interactions with the NDIS.

Our individual advocacy work relies on building strong relationships with people living with disability, family members and their loved ones. Similar issues are raised time and time again, and are confirmed by all the advocacy organisations in our state-wide and national networks. Leadership Plus is also the advocacy agency selected to conduct the Decision Support Pilot in Victoria, a program initiated by the Department of Social Services to ensure that particularly vulnerable people with no other supports are able to engage with the NDIS.

Our daily experience, complemented by our advocacy activity and our interaction with the other Decision Support agencies via monthly teleconferences we have facilitated, puts us in a powerful position to identify and articulate the issues relating to providing support for decision making for vulnerable Australians, and to pinpoint important solutions to enable the NDIS to make effective policy and practice improvements.

QAI and Leadership Plus recommendations

1. Embed support for decision-making into all areas of practice within the Agency, rather than an isolated policy. The proposed policy does not appear to convey the complexity of decision-making support, the often challenging life circumstances of individuals who require it and the associated skills required to effectively work alongside a person with impaired decision-making abilities. The policy must encompass a new approach to how people engage with and support people with disability across their whole NDIS journey.
2. Further develop and publicise the detail of how the Decision-Making Capability Framework will be applied in day-to-day practice.

3. Explicitly recognise *supported decision-making*, not just *support for decision-making*. By inadequately differentiating between support for decision-making and supported decision-making, and in failing to identify when some people with disability require specialist decision-making support, the unique needs of the most vulnerable participants risk being neglected. The policy must recognise and assist participants who require skilled, and separately funded, avenues of *independent* decision-making support. That is, support that is different to, and which goes beyond, the supported decision-making practices expected of all stakeholders who come into contact with a person with disability. This nuance must be reflected in the proposed actions of the policy.
4. Ensure independent decision-making support continues to be recognised, promoted, and appropriately funded. Support from independent decision-support advocacy services is materially different to ‘support for decision-making’ that a participant might receive from paid support workers.
5. Recognise participant’s rights and views with regards to their decision-support needs. Even if unintentional, the language used in the policy presents as paternalistic and conveys a message that a participant’s access to decision-making support will be determined by the Agency. This fails to reflect the ethos of the CRPD which requires people with disability to make their own decisions, including deciding upon how their decision-support needs can best be met. The policy’s starting point must be to establish the views of the participant with respect to how best to meet their decision-support needs.
6. Remove any implications that the Agency will assess capacity. The terminology used in the Decision-Making *Capability* Framework is concerning for its similarity to the concept of decision-making *capacity*. It can easily be misinterpreted that the Agency is proposing to assess a participant’s decision-making capacity, as opposed to establishing an understanding of their decision-making support needs, as is presumed to be the intention behind the framework. Whilst subtle, the difference is important. The emphasis should be on establishing decision-support needs as opposed to capabilities or capacity.
7. Require NDIS service providers to adhere to supported decision-making practices. Competency in supported decision-making practices could become part of a provider’s registration requirements and/or regular auditing processes. Relying upon the goodwill of service providers to adopt supported decision-making practices alone is insufficient. Structural changes to auditing processes and costings are also necessary to facilitate the cultural change required.
8. Modify nominee processes and policy to better reflect the CRPD and decision-support principles. Whilst many nominees successfully perform their role, not all nominees adhere to their duties in the Operational Guideline. A number of recommendations are provided accordingly.
9. Strengthen safeguards around guardianship and administration applications initiated by NDIS service providers. For example, requiring NDIS service providers to take an additional step before submitting an application to the relevant state or territory tribunal, such as liaising with the NDIA or NDIS Quality and Safeguards Commission. Measures that hold service providers to account for making unsubstantiated applications should also be considered, such as penalty notices. At a minimum, the NDIS Quality and Safeguards Commission must collect relevant data.
10. Maintain the presumption of capacity in all of the Agency’s processes. The proposal to ‘introduce a formal process to identify a participant’s decision-making capacity’ is deeply concerning. Capacity must not be assessed to satisfy the Agency’s administrative processes. Capacity must only ever be assessed if it is clinically indicated, as a last resort measure following the application of supported decision-making practices. To assess decision-making capacity purely owing to the presence of impairment is discriminatory against people with disability.
11. Consult further with Aboriginal and Torres Strait Islander people with disability and their representatives to ensure proposed measure appropriately meet the decision-support needs of Aboriginal and Torres Strait Islander participants.

Introduction

QAI and Leadership Plus welcome the focus on the rights of people with disability to make their own decisions on an equal basis with others. For too long, the self-determination of people with disability has been denied as a result of ‘best-interest’ decision-making practices, where the will and preferences of people with disability are denied on account of their perceived cognitive capabilities. Despite the rising dominance of the social model of disability, paternalistic attitudes that pathologize disability continue to prevent people with disability from exercising individual autonomy. Yet, the social model of disability requires an ‘ecological view of self-determination’.¹ That is, a focus on the environmental factors that facilitate the exercise of legal capacity, where the onus of change is placed upon ‘supporters, rather than those being supported’.² The model of supported decision-making envisioned by Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) offers such an approach, however its implementation into Australian policy has met resistance. The introduction of the National Disability Insurance Scheme (NDIS) and the marketisation of disability services has further complicated matters. Whilst decision-making opportunities for people with disability have increased under the NDIS, with its flagship focus on optimising ‘choice and control’, self-interested service providers remain at liberty to put their own needs ahead of the people they support and, in some situations, this has resulted in the exploitation of people with disability, including people with impaired decision-making skills.

Renewed attention to how the NDIS can ‘promote, encourage and facilitate a positive change in access to support for decision-making’³ for scheme participants is therefore extremely welcome. Whilst the proposed Support for Decision Making policy highlights several pertinent issues, QAI and Leadership Plus fear its substance does not adequately reflect the complexity of decision-making support, nor the scale of cultural change required to achieve the paradigm shift intended by Article 12 of the CRPD. This submission will begin by providing general feedback on the Support for Decision Making policy, before addressing some of the key consultation questions and providing comment on some of the Agency’s proposed actions. It draws upon QAI and Leadership Plus’s experience delivering the Decision-Support Pilot and includes direct feedback from NDIS participants in Appendix A.

General feedback

There are several positive features of the Support for Decision Making policy, including:

- Placing the discussion of decision-making support within a human rights framework, referencing in particular Australia’s legal obligations under the CRPD and the rights of people with disability to receive support when making decisions
- Acknowledging the link between exercising decision-making autonomy, increased quality of life and inclusion within the community
- Recognising the importance of ‘dignity of risk’ and the right of all people, including people with disability, to take chances and learn from their experiences
- Conceding that to date, the National Disability Insurance Agency (the Agency) has relied too heavily upon nominees and that substitute decision-makers, such as nominees, do not always act in accordance with a participant’s will and preferences

¹ Watson, J. (2016) *Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realization of Article 12 for People with Severe or Profound Intellectual Disability*, *Laws*, 2016, 5 ,6; p 3

² *Ibid*

³ National Disability Insurance Agency (June 2021) *Consultation Paper: Supporting you to make your own decisions*, p 23

- Acknowledging the important role of the Agency in ensuring that all participants receive adequate decision-making support regarding their NDIS journey
- Indicating an intention to understand a participant's need for support to make decisions, document the availability of a participant's decision-making supports, consider how best to grow a participant's ability to make decisions and develop a range of related resources
- The proposed idea of utilising Information Linkages and Capacity Building supports to build peer support networks and self-advocacy skills of participants, particularly participants who are isolated and who have limited informal supports

Further, the lengthy consultation period and extended deadline for written submissions (notably longer than recent Agency consultation processes) has also been appreciated. However, QAI and Leadership Plus also hold a number of reservations. Firstly, the proposed Support for Decision Making policy does not appear to convey the complexity of decision-making support, the changing and often challenging life circumstances of individuals who require it and the associated skills required to effectively work alongside a person with impaired decision-making abilities. Such nuanced work does not readily fit into continuums or frameworks, nor can it be reduced to a process wherein the Agency completes an isolated assessment of a participant's perceived decision-making capabilities, or worse, decision-making *capacity*. It requires relationships and the establishment of trust. It is a constantly evolving concept, fluctuating with changing environmental factors. And it is sometimes necessary beyond key life transition stages, with some participants requiring decision-making support for day-to-day decisions. The policy must therefore encompass a new approach to *how* people engage with and support people with disability across their whole NDIS journey. Support for decision-making must become embedded into all areas of practice within the Agency, rather than the focus of an isolated policy. For example, providing consistent information to participants and adhering to participant requests for contact via a designated support person, are but two steps that the Agency can take to maximise the decision-making capabilities of participants.

Secondly, the proposed policy lacks sufficient detail regarding how the Decision-Making Capability Framework will be applied in day-to-day practice. For example, will it be applied at the start of a person's journey, or at key life stages, or for all decisions? Who will apply it, and with what information and evidence, and with what skills? What will be the outcome? Further information regarding the suggested application of the framework is needed.

Thirdly, the difference between *support for decision-making* and *supported decision-making*, whilst addressed superficially, does not appear to be adequately captured, with the effect of overlooking the unique decision-support needs of the scheme's most vulnerable participants. It is true that all people utilise *support for decision-making* from a range of informal, formal, paid and unpaid supports and resources to make decisions. It is also true that all NDIS participants would benefit from increased support for decision-making, particularly considering the scheme's commitment to maximising choice and control. For example, they may benefit from peer support networks, or drawing upon the informal support of family and friends who, incidentally, should be educated on how to ensure the will and preferences of the person they are supporting remain central to all decision-making processes. It is also correct to state that *supported decision-making* describes a 'process of supporting people to make decisions.'⁴ However, some people with disability have decision-support needs that are extremely high and complex. For these participants, the supported decision-making practices of people around them, including paid support workers or Agency staff, will not be sufficient to adequately meet their decision-support needs. For example, the person may have no informal supports at all, despite efforts to build networks and indeed they may never be able to build such supports. They may experience cognitive challenges,

⁴ National Disability Insurance Agency (June 2021) *Consultation Paper: Supporting you to make your own decisions*, p 5

have difficulty processing abstract concepts or experience poor memory recall. They may experience expressive communication challenges. These participants are extremely vulnerable to undue influence when their only form of decision-making support comes from paid support workers or service providers whose own interests will inevitably conflict with those of the participant. Their needs are heightened further by the 'labour of choice' facing participants, where an increase in frequency and complexity of decision-making due to the marketisation of disability services requires 'significant cognitive, relational and emotional work'.⁵ These participants require specialist decision-making support from independent, professional advocates who are trained in working alongside participants to elicit their will and preferences and to maximise their autonomy. This kind of decision-making support is materially different to the supported decision-making practices that a participant might utilise from paid support workers. By inadequately unpacking the distinctions between support for decision-making and supported decision-making, and in failing to identify when some people with disability require *specialist* decision-making support, the unique needs of the most vulnerable participants risk being neglected. The policy must therefore include the ability to recognise and assist participants who require skilled, and separately funded, avenues of *independent* decision-making support. That is, support that is different to, and which goes beyond, the supported decision-making practices expected of all stakeholders who come into contact with a person with disability. This nuance must be reflected in the proposed actions of the policy.

Fourthly, the proposed Support for Decision-Making policy presents as somewhat paternalistic in its assertion 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'.⁶ Even if unintentional, the language used conveys a message that a participant's access to decision-making supports is *determined by the Agency*, who thus retain control over the participant and their access to decision-making support. This fails to reflect the ethos of the CRPD which requires States Parties to uphold the rights and dignity of all people with disability to make their own decisions, including deciding upon how their decision-support needs can best be met. This is particularly critical in the absence of a legally appointed substitute decision-maker. The policy's starting point must therefore be to establish the views and preferences of the participant with respect to how best to meet their decision-support needs. It must be centred upon the premise that, at all times, people with disability are presumed to have decision-making capacity. Placing the Agency into a position of authority over a participant's decision-support needs is a continuation of the ideology behind the medical model, which denies decision-making autonomy on account of a person's impairment and fails to recognise the individual as the expert in their own life. It also has the potential to add additional and unwelcome bureaucracy to a scheme already overburdened with administrative processes.

Fifthly, the terminology used in the Decision-Making Capability Framework is concerning for its similarity to the concept of *decision-making capacity*. That is, it can easily be misinterpreted that the Agency is proposing to assess a participant's decision-making capacity, as opposed to establishing an understanding of their decision-making support needs, as is presumed to be the intention behind the framework. Whilst subtle, the difference is important. People with disability have historically had their legal capacity denied on the basis of arbitrary conclusions drawn from the presence of an impairment. To this day, people with disability continue to encounter unjustified challenges to their decision-making capacity, most notably in healthcare settings where the principles of supported decision-making are yet to infiltrate the day-to-day practices of many healthcare professionals. Instead, there must always be a presumption of decision-making capacity. It must only ever be assessed when there is reason to believe there is impaired capacity, there is a need for a decision *and* there is

⁵ Independent Advisory Council of the NDIS (July 2019) *Support for decision-making in the NDIS*, p 10

⁶ *Ibid*, p 9

a risk that in the absence of assessing capacity (for the purposes of establishing decision-support needs, including the potential requirement for a substitute decision-maker) the person's needs will not be met and their interests inadequately protected.⁷ Moreover, decision-making capacity must only be assessed by appropriately trained clinicians. The focus of the policy, and the terminology used therein, should therefore convey an intention to understand and establish the participant's preferences for decision-making support, their decision-support needs and how they might be strengthened, and documenting this accordingly. For example, whether they require communication aids or the presence of an interpreter. As the Independent Advisory Council (IAC) recommended, the policy must establish a framework that 'in a simple informal way, assesses the quality of current informal support for decision-making...to mitigate the risk that participants in need of decision-making support are not identified. The practice guidance would include pathways to decision making support'.⁸ The emphasis should thus be on establishing the decision-support *needs* as opposed to the capabilities or capacity of the participant.

Finally, a Support for Decision Making policy requires an associated investment in supported decision-making practices by NDIS service providers. Competency in supported decision-making practices and policies that optimise the rights of people with disability to make their own decisions could become part of a provider's registration requirements and/or regular auditing processes, where service providers are required to demonstrate proficiency in supporting participants to exercise their individual autonomy and can be held to account in the absence of such a commitment. QAI and Leadership Plus support the recommendation of the IAC that 'The NDIA...make representations to the Quality and Safeguards Commission to reinforce the importance of monitoring Practice Standards requiring the demonstration of *active decision making and individual choice...support for each participant*'.⁹ QAI and Leadership Plus further support the IAC's statement that 'The NDIA Price Catalogue item *Assistance with decision making, daily planning and budgeting* in the domain of Improved Daily Living, is priced below the level of basic support work. Supporting a person to make decisions and build their competence and confidence in making decision is a skill set for which training is necessary. It should be priced above, not below, the level of support work.' Relying upon the goodwill of service providers to adopt supported decision-making practices alone is insufficient. Structural changes to auditing processes and costings are also necessary to facilitate the cultural change required.

How can we make sure the right people are helping? How can we help reduce undue influence?

Ensuring that people with disability receive appropriate support to make decisions is a critical objective of the policy. People with impaired decision-making skills are susceptible to undue influence from others, including well-meaning family members or friends, and some participants may be unaware of the extent to which they are subject to the will and preferences of those around them. Accordingly, there must be sufficient safeguards in place to minimise this risk and to identify when participants are not being supported appropriately.

In preparing our submission, QAI and Leadership Plus obtained feedback from current NDIS participants regarding their views on how the Agency can ensure that the right people are helping them. One participant stated simply, "Ask me if the right people are helping me. Ask me things like how regularly we speak, if they ask me things and if I trust them". Another said "Having people help me to make decisions who have no reason to

⁷ *Guardianship and Administration Act 2000* (Qld), s 12.

⁸ Independent Advisory Council of the NDIS (July 2019) *Support for decision-making in the NDIS*, p 28

⁹ *Ibid*, p 29

influence. Having someone regularly check things like plan nominee". There must be processes that meaningfully ascertain the views of participants as to the appropriateness of their support, and rules that limit who can provide such support.

QAI and Leadership Plus support the intention of the Agency to reconsider the policies pertaining to nominee arrangements. A nominee is 'a person who is appointed in writing, at the request of a participant, or on the initiative of the NDIA, to act on behalf of, or make decisions on behalf of a participant for the purposes of the NDIS Act.'¹⁰ Nominees have a 'duty to ascertain the wishes of the participant and act in a manner that promotes the personal and social wellbeing of the participant'¹¹. Whilst many nominees successfully fulfil this requirement, not all nominees perform their duties in accordance with the Operational Guideline. Further, the extent to which nominees are aware of, let alone comply with, their duty to develop 'the capacity of the participant to make their own decisions, where possible to a point where a nominee is no longer necessary'¹² is similarly questionable. As the IAC has stated, 'whilst the Act requires nominees to ascertain the wishes of the participant, consult, develop the capacity of the participant to make decisions and avoid or manage conflicts of interest, there is no guidance or monitoring as to the way in which nominees carry out their role'.¹³

QAI and Leadership Plus have encountered situations where nominees have failed to act in a manner that promotes the personal and social wellbeing of the participant, where the nominee exerts control over the participant and makes decisions in accordance with their own interests. This is illustrated in the following case study:

Case study 1

Hannah* is a young woman who sought advocacy assistance at a time of crisis. Hannah's father, whom she had appointed as her plan nominee, had decided to move her from the home where she had been living with her brother and five others for the past three years. Hannah didn't want to move and the proposed moving date was within that same week.

Hannah had been working with her support coordinator to identify an appropriate home in which she could live alongside a fewer number of her peers, but had not yet made up her mind and did not want to move to the home her father had hastily secured on her behalf, which she understood housed three older men and which was some distance from her formal supports with whom she'd built relationships over the years.

Hannah's father had not involved her in the decision-making process. He had not ascertained her wishes, and due to the nature of their relationship which was characterised by a history of trauma and abuse, Hannah was extremely anxious about upsetting him. Hannah's self-harming behaviour worsened as a result of the situation.

Hannah explained she had consented to her father being her plan nominee at a time when she was unwell and only had vague recollections of that time.

Hannah needed significant support from an independent advocate and her existing formal supports to be empowered and supported to make the decision to cancel the appointment of her father as her plan nominee. Hannah wavered frequently during conversations with her independent advocate, particularly

¹⁰ National Disability Insurance Agency, *Nominees Operational Guideline – Overview*; <https://www.ndis.gov.au/about-us/operational-guidelines/nominees-operational-guideline/nominees-operational-guideline-overview>

¹¹ National Disability Insurance Agency, *Nominees Operational Guideline – Duties of nominees*; <https://www.ndis.gov.au/about-us/operational-guidelines/nominees-operational-guideline/nominees-operational-guideline-duties-nominees>

¹² Ibid

¹³ Independent Advisory Council of the NDIS (July 2019) *Support for decision-making in the NDIS*, p 5

after being subject to verbal abuse from her father. Ultimately, the appointment of Hannah's father as her plan nominee was cancelled, however the risk that Hannah will be subject to the influence of her father and again appoint him as her plan nominee persists, jeopardising her right to choice and control as to how she lives her life.

**Name has been changed to protect confidentiality*

QAI and Leadership Plus therefore recommend the following:

1. Informal decision-making support arrangements should be maximised to the greatest extent possible, with nominee appointments genuinely only occurring as a last resort measure. Informal decision-making supporters such as family members or friends (as identified by the participant) should be supported by the Agency via training and education, to implement supported decision-making practices to assist participants to exercise their decision-making rights. The current culture, in which nominee appointments and/or the consent of nominees are routinely sought to satisfy Agency administrative process and/or risk management objectives, needs changing. Information for alternative contacts for the participant can be recorded for use in emergencies, instead of nominee appointments occurring for this reason.
2. Participants who do not have informal decision-making support and for whom decision-making support is likely to come from paid service providers, should be referred to independent, decision-support advocacy services before formal nominee appointments are considered. Continued funding and expansion of Decision-Support 'Pilot' programs is therefore required.
3. In the event that a nominee appointment is needed or requested, such an appointment should be made separately to a plan review meeting. Discussions regarding the appointment of plan nominees, particularly in the presence of family members or support coordinators, can be challenging for participants who may feel obliged to agree with the suggested appointment, to avoid an embarrassing or awkward situation. Nominee appointments should not occur following casual conversations in plan review meetings, but should follow a formal and separate process whereby the genuine wishes of the participant are obtained independently from discussions regarding their funding, and concerted efforts have been made to ensure the participant is well-informed as to the scope of a nominee's role.
4. All nominees must be provided with formal training and education from the Agency with respect to their duties to build the capacity of participants, to ascertain the will and preferences of the participant and to avoid any conflicts of interest. In the absence of specific training on supported decision-making principles, people revert to 'best-interests' approaches. Whilst it may be well-intentioned, it is rooted in ableist ideology and fails to implement the rights-based framework required under Australia's commitment to the CRPD.
5. Greater consistency is needed regarding who is eligible to be appointed as a nominee. QAI and Leadership Plus have encountered situations where participants have had allied health professionals, support coordinators or formal service providers perform the role of nominee. These appointments are inappropriate given the market-based model of the NDIS and the conflicts of interest frequently realised in these circumstances. Whilst the NDIA Operational Guideline states that individuals associated with the NDIA (such as support workers) cannot be appointment as a nominee, QAI and Leadership Plus are aware of instances where this has occurred. Greater awareness of, and consistency in adherence to, this rule is therefore urgently required.
6. Regular review of nominee arrangements is necessary, *following meaningful engagement with the participant with respect to their nominee arrangements*. This will require Agency staff to be

demonstrably competent in engaging with people with disability, including people with limited decision-making skills, in ascertaining the will and preferences of people with disability with regards to all of their NDIS related matters, including nominee arrangements. This requires knowledge of, and skills in, communicating with people with varying communication needs. It also requires competency in discussing nominee arrangements in a way that will leave open the possibility of identifying situations where the participant is being subject to undue influence, including situations where the participant is not aware of this. Thus, superficial questions such as 'are you happy with your current nominee appointment' during a phone call review, will be insufficient. This is because the participant could be in the presence of their nominee, and the participant may feel uncomfortable asking them to be removed from the conversation. Similarly, the plan nominee may use threatening or intimidating body language to exert pressure on the participant to agree to their continued appointment, all of which would not be apparent to a planner over the telephone. Written correspondence is similarly susceptible to abuse. Agency staff must therefore become accustomed to meeting with the participant in person, preferably alone or in an environment where the participant is free to express their views. Suggested questioning can be found in resources such as the Queensland Capacity Assessment Guidelines, for example, 'Do you feel as if someone is not letting you do what you want to do?' or 'What does X think you should do? What do you think will happen if you don't do that?'.¹⁴ Agency staff must ensure that the participant has access to information in the appropriate format, must provide the participant with the necessary time to process and consider the information before providing an answer, and ensure that they have an opportunity to discuss the information with relevant others, before making a decision. In other words, Agency staff 'need to use core decision support strategies to mitigate the limitations'¹⁵ of their limited knowledge of the person. As such, QAI and Leadership Plus are concerned that the 'desktop review' of nominee arrangements as proposed in Appendix C, will be wholly insufficient.

7. Introduce processes such as placing a red flag on a participant's plan or Agency record when concerns about the intentions or actions of a nominee are made known to the Agency.
8. Consider avenues of complaint and/or redress for participants whose nominee fails to act in accordance with their duties, causing harm to the participant.
9. Ensure the Agency does not automatically consider a participant's decision-support needs to be adequately met through the appointment of a nominee, in the knowledge that nominees are substitute decision-makers and as such, carry the risk of neglecting their obligations to support the participant via supported-decision making practices.
10. Reconsider the policy authorising the appointment of nominees at the initiative of the Agency CEO, who has the authority to appoint a substitute decision-maker with comparable powers to a guardian but who does so in the absence of the transparency, independence, and accountability of a tribunal. Further clarification regarding the circumstances in which such appointments are made, is required. For example, is an independent decision-making capacity assessment sought? If so, at whose expense? QAI and Leadership Plus recommend the Agency consider delegating these decisions to an independent body, such as the NDIS Quality and Safeguards' Commission, in order to address the conflict of interest inherent in these appointments.

¹⁴ Queensland Capacity Assessment Guidelines 2020, p 37

¹⁵ Independent Advisory Council of the NDIS (July 2019) *Support for decision-making in the NDIS*, p 24

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

Decision-support is a novel concept in a society where legal systems traditionally only recognise independently exercised autonomy and decision-making.¹⁶ However, the social model of disability and Article 12 of the CRPD requires the provision of ‘supports...to allow an individual with cognitive disability to engage in decision-making, either independently or with assistance from others’.¹⁷ It is therefore important that decision-supporters understand the legal imperative behind decision-making support, the human rights framework underpinning it and the evidence base supporting its efficacy.

Firstly, decision-makers need to understand the principles of supported decision-making. The Australian Law Reform Commission (ALRC) suggests that rather than considering whether a person has capacity for a matter, focus should be placed upon the type of support that is required. The ALRC sets out four National Decision-Making Principles:

1. All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
2. Persons who require support in decision-making must be provided with the support necessary for them to make, communicate and participate in decisions that affect their lives.
3. The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives. When the will and preferences or likely will and preferences of the person cannot be obtained, the decision-maker must act to promote and safeguard the human rights of the person in a way that is least restrictive of those rights.
4. Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.¹⁸

Further resources can be drawn upon. The La Trobe Support for Decision Making Practice Framework provides an iterative 7-step guide to supported decision-making, informed by the principles of ‘commitment (i.e. in the context of relationship), orchestration and reflection and review’, to be delivered through strategies that are tailored to the individual.¹⁹ Similarly, the Victorian Department of Human Services developed a Supported Decision-Making guide that provides 7 decision-making principles. 1) Everyone has the right to make decisions about the things that affect them; 2) Capacity to make decisions must be assumed; 3) Every effort should be made to support people to make their decisions; 4) Capacity is decision-specific; 5) People have the right to learn from experience; 6) People have the right to change their minds; 7) People have the right to make decisions others do not agree with.²⁰ The General Principles of the *Guardianship and Administration Act 2000* (Qld) add further guidance, for example stating the importance of maintaining the adult’s existing supportive

¹⁶ Arstein-Kerslake, A., Watson, J., Browning, M., Martinis, J. and Blanck, P. (2017) Future Directions in Supported Decision-Making, *Disability studies quarterly*, vol 37, no 1, p 5

¹⁷ Ibid

¹⁸ Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws*, p 11

¹⁹ Bigby, C., & Douglas, J. (2015). *Support for decision making – A practice framework*. Living with Disability Research Centre, La Trobe University; <http://hdl.handle.net/1959.9/556875>

²⁰ Victorian Department of Human Services (2012) *Disability Services – Supporting decision-making: A guide to supporting people with a disability to make their own decisions*

relationships, maintaining an adult's cultural and linguistic environment and values, and maximising the adult's participation in decision-making.²¹

Secondly, decision-supporters need to understand the concept of decision-making capacity and realise that medical assessments of cognition do not automatically equate to a determination that a person does or does not have legal decision-making capacity for a matter. Instead, the social context in which decision-making takes place must be considered. The Queensland Capacity Assessment Guidelines outlines five principles to be applied when considering an adult's capacity, including the principle that capacity is *decision-specific* and *time-specific*.²² Only in limited circumstances, where a person cannot be assisted to understand, consider and communicate a decision, where there is a need for relevant decisions to be made and the appointment of a substitute decision-maker (preferably termed a 'representative' decision-maker) is necessary to protect the adult's interests, should a person be deemed to have impaired decision-making capacity for that matter.

Thirdly, decision-supporters must understand the concept of dignity of risk and the rights of people with disability to take chances, make mistakes and to learn from their experiences. Decision-supporters also need to be familiar with the types of barriers that people with impaired decision-making skills might encounter when making decisions. For example, people with intellectual disability often take a passive communication style, known as acquiescence, in order to mask their disability and avoid the stigma associated with their impairment.²³ This may lead to the person agreeing to things that they are not comfortable with or do not fully understand.

Fourthly, decision-supporters need to be self-aware and reflective of their own personal values and beliefs and recognise when they are influencing the decision-support process. Decision-supporters also need to have a 'positive perception of the ability of those they support to lead self-directed lives' as people are more likely to lead self-determined lives when those around them believe it is possible.²⁴

Ultimately, decision-supporters must not tell participants what to do. In the words of one NDIS participant who described a time when a decision-supporter successfully helped them, they replied: "*No one told me what to do, they gave me options and gave me information so that I could understand. I have a relationship with them, and they know me*".

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

Decision-support must always begin with a presumption of capacity and must be provided in a manner that is least restrictive of a person's human rights. Informal arrangements must be maintained and preserved where possible and formal appointments of substitute decision-makers must genuinely be measures of last resort. The individual circumstances of the person also need to be considered, such as whether they are receiving

²¹ *Guardianship and Administration Act 2000* (Qld), section 11 B

²² Queensland Capacity Assessment Guidelines 2020, p 9; 1) Always presume an adult has capacity; 2) Capacity is decision-specific and time-specific; 3) Provide the adult with the support and information they need to make and communicate decisions; 4) Assess the adult's decision-making ability rather than the decision they make; 5) Respect the adult's dignity and privacy

²³ WWILD Sexual Violence Prevention Association, *How to Hear Me*, https://wwild.org.au/wp/wp-content/uploads/2020/09/How_To_Hear_Me_plus_covers_website-version-Final.pdf, p 36

²⁴ Watson, J. (2016) *Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realization of Article 12 for People with Severe or Profound Intellectual Disability*, *Laws*, 2016, 5, 6; p 6

decision-support from formal or paid support workers or service providers in the absence of informal networks. Referrals to independent advocacy organisations in these situations will ensure their will and preferences are protected and not usurped by the interests of those around them.

The Decision-Support Pilot (DSP) exemplifies the optimal way of supporting people with disability to make decisions about their NDIS plan. The DSP provides decision-making support for potential and current NDIS participants, aged 18 years and over, with limited decision-making capacity and no other appropriate decision-making support, with key interactions with the NDIS. It requires decision-supporters to build knowledge of the person's context by building a respectful and supportive relationship based upon trust. The decision-supporter seeks to understand the person's communication needs and assists them to receive information in relevant formats, including via relevant communication aids, by understanding facial expressions or gestures and taking breaks as required. They consider the decision-making history of the person, as well as any other expert or relevant information to the decision, such as its urgency, its sensitivity and/or whether the person is experiencing any personal issues that might impact their decision-making. The physical environment of the discussions is considered and managed, and potential sources of informal decision-support are identified and accessed if appropriate. Importantly, the person is given sufficient time to consider their options and is permitted to delay decision-making and to seek further advice as necessary. The decision-supporter anticipates that the person may change their mind and checks in again with the individual a few days after a decision has been made. Essentially, the decision-supporter 'provides information in a manner that is right for the individual, breaks down decisions into smaller more easily identifiable components, provides opportunities for the person to try different options, provides opportunities to talk through the options, decisions and implications with the person and others as appropriate, and allows the person to experience the safe consequences of decisions.'²⁵ It is illustrated in the following case study:

Case study 2

Tracey* lives alone in a small town in regional New South Wales. She is an engaging, intelligent woman who has some strong and fixed opinions arising from a long history of difficult personal experiences. Tracey has multiple psychosocial disabilities as well as regular migraines. These conditions impair her cognitive function and make it difficult for her to function, including managing day-to-day affairs. Her speech and interpersonal interactions become difficult if concentration is lost and she can become over-reactive and physically ill when trying to prepare for commitments. When very unwell, Tracey requires support with domestic assistance, meal preparation, shopping, appointments etc. For approximately one week per month, Tracey is almost completely unable to make basic decisions about her day, and especially more complex decisions about the NDIS supports she needs. Tracey is also trying to care for her ageing parents in the absence of other family support. Unfortunately, despite regular attempts to create new connections through her community, Tracey has no other close relationships she can call upon. Tracey is her own legal decision maker and has no NDIS Plan Nominee.

Tracey sought assistance to prepare for her first NDIS Plan Meeting and implementation of her first NDIS Plan. At the time of her Intake, Tracey had achieved NDIS Access and a Plan Meeting had been scheduled – this was soon changed to allow time to prepare. Tracey and the advocate undertook structured conversations during Face-to-Face meetings to ascertain her aspirations, goals, and to determine what supports were needed to achieve her goals. These were recorded in a document which was sent to the LAC ahead of the newly scheduled Plan Meeting. A completed NDIS Planning Booklet 2 was also sent. Sending these documents ahead of the meeting served two purposes: one was to enable the LAC to become familiar

²⁵ Independent Advisory Council of the NDIS (July 2019) *Support for decision-making in the NDIS*, p 14

with, and thus better relate to Tracey as a person at the Plan Meeting; and two – providing insight into her situation as well as detailed personal information ahead of time, considerably shortened what can sometimes be a very lengthy meeting. Both of those imperatives were very important to Tracey.

Tracey subsequently received her first Plan. What followed was a great deal of nuanced, individualised support on the part of the advocate, who assisted Tracey to make decisions that suited her preferences in a way that ensured Tracey was informed as to the potential consequences of engaging certain providers. Understanding Tracey's history was integral to this. Tracey previously worked in the disability sector and was concerned about her privacy in the event of engaging local, registered NDIS providers. Protecting her privacy was critical to maintaining her mental health and well-being. Tracey also had a preference for alternative medicines. The advocate assisted Tracey to explore the availability of, and cautions around, engaging independent contractors. Tracey subsequently chose not to engage local, disability providers and engaged independent contractors instead.

The issues that were non-negotiable for Tracey are unlikely to be important to most other participants. Her experience in the disability sector led her to have assumptions about what supports she could and could not purchase. Her decisions could appear ill-informed to someone who did not know Tracey, and certainly presented challenges. The advocate sought to:

- correct what Tracey believed to be accurate information but which was incorrect
- provide current guidelines and documents rather than old versions that Tracey had sourced herself
- help Tracey understand the ramifications of becoming an employer as opposed to being someone who simply “contracts” an independent provider
- identify and engage a Plan Manager who could work to uphold her desire for privacy
- recognise and manage their own biases as Decision Supporter, balancing Tracey's right to choice and control with the advocate's responsibility to ensure Tracey is provided with information that is comprehensive, yet delivered in a way which is accessible and likely to increase the chance of Tracey making well informed decisions
- use innovative approaches to sourcing potential local providers whilst upholding Tracey's desire to not inform those providers that of her NDIS Participant status
- explore the possibility of engaging a remote Support Coordinator who will not know her or need to meet Face to Face
- regularly revisiting the notion of “Reasonable and Necessary” supports and ensuring Tracey understands the possible consequences of purchasing supports that are potentially inappropriate to purchase via her NDIS Plan
- emphasise the aspects of her life that fall within the health domain as opposed to disability and ensure supports engaged via her NDIS Plan will address her disability related needs
- gather information about the obligations of registered and unregistered providers and provide sufficient information to support sound decision making during the selection of her providers, the expectations she is entitled to have of them, and what moral imperatives are at play when they don't know they have become an unregistered NDIS Provider by virtue of being paid by Tracey's NDIS funds to deliver their services
- accommodate Tracey's limited computer skills and device limitations

Significant effort was required to research information and provide it in a format that was clear and appropriate. To date, Tracey has engaged some contractors on a casual basis to attend to specific tasks. This has been a good way for her to get a “feel” for how to select, engage, and pay these providers and to then get reimbursed by her Plan Manager.

**Name has been changed to protect confidentiality.*

These strategies apply equally to formal and informal supporters as well as to Agency staff. The IAC stated that NDIA staff and LAC partners would benefit from training and development to strengthen their role in supporting participants to make decisions. Greater consistency in the appointment of a participant's planner or LAC would assist by facilitating the establishment of a relationship, reducing the provision of inconsistent information and decreasing resultant complaints.

How can we help reduce conflict of interest?

Conflicts of interest are abundant in a market-based scheme where participants and service providers alike are free to make decisions in accordance with their own interests. Whilst this facilitates people with disability exercising increased choice and control, people with impaired decision-making skills are at risk of exploitation, a risk heightened further in the absence of appropriate safeguards. Potential conflicts of interest situations must therefore be anticipated and proactively prevented through regulation. Greater consistency in the application of rules that prevent allied health professionals, support coordinators and paid support workers acting as plan nominees would assist in this regard.

One area where NDIS participants are having their decision-making rights denied due to conflicting interests is the increasing number of guardianship and administration applications being initiated by NDIS service providers.²⁶ A number of these applications are being submitted without merit and are based upon unsubstantiated claims of incapacity, with little to no evidentiary basis. As tribunals are not bound by rules of evidence, medical and allied health reports prepared for NDIS access or plan purposes are often used to support these applications, despite their content not pertaining to issues of decision-making capacity. Whilst many applications may have benevolent intentions, some are occurring in situations where prior to the NDIS, informal decision-making arrangements were working well. This is because the NDIS has introduced a level of formality and bureaucracy into disability service provision not previously seen in the sector. Even more concerning are the applications submitted by NDIS service providers in relation to participants with substantial funding packages following a disagreement between the service provider and the participant and/or familial guardian. In these situations, the service provider typically applies for the appointment of the Public Guardian as it is well known within the disability sector, that the Public Guardian almost exclusively enters into service agreements with registered service providers as opposed to smaller, independent or unregistered providers who may be preferred by participants. The conflict of interest inherent in situations where the service provider has a vested interest in maintaining a service agreement with a participant who has a substantial funding package is alarming. In the event of a disagreement, the risk of the participant ceasing services with the provider is mitigated by seeking the removal of the participant or their family member's decision-making rights and with the subsequent appointment of the Public Guardian. This is illustrated with the following case study:

Case study 3

Roger*, in his 50's, has an intellectual disability and a substantial NDIS funding package that provides 1:1 in home support. He lives in his own home and decisions about his healthcare, finances and NDIS supports are made by his sister Rachel, who was appointed as Roger's guardian following the death of their mother. No concerns regarding this arrangement were ever raised by Roger or anyone else until 2019, when Roger's

²⁶ Queensland Advocacy Incorporated (2021) Increasing Guardianship and Administration Applications in the NDIS, <https://qai.org.au/2021/03/26/increasing-guardianship-applications-in-the-ndis/>

service provider was taken over by another registered provider, Provider X. The new workers supporting Roger from Provider X were less communicative with Rachel and before long, a dispute arose between Rachel and Provider X regarding the level of support they were providing to Roger. Provider X became concerned it was at risk of losing Roger's service agreement. Email correspondence between staff at Provider X referenced management concern about losing a "\$90,000 client". Provider X support workers took Roger to an appointment with his doctor where they encouraged Roger to tell the doctor that Rachel had been abusing him. Roger became very distressed and confused. Provider X used the doctor's report in a subsequent application to QCAT for the appointment of the Public Guardian and Public Trustee and to remove Rachel as Roger's decision-maker. Rachel terminated Roger's service agreement with Provider X and employed another service to support Roger. Roger remained significantly distressed in the lead up to the QCAT hearing and expressed concern that Rachel would be taken away from him. At the hearing, which took two full days, the application was ultimately dismissed and Rachel remained as Roger's substitute decision-maker. Roger's anxiety then dissipated and his relationship with Rachel has returned to its pre-existing state.

**Name has been changed to protect confidentiality.*

This case study highlights a concerning trend where NDIS participants are inappropriately having their legal capacity called into question. The financial and emotional toll placed upon a participant forced to defend unfounded and sometimes vexatious applications for guardianship and administration cannot be overstated. The affront to a person's dignity and their human right to equality before the law causes significant psychological distress. Interim orders are also sometimes imposed on the basis of inadequate evidence and without hearing the wishes of the person. Whilst some of these applications are correctly dismissed, others are not and lead to the appointment of a substitute decision-maker in situations where it is neither required nor appropriate.

There is a lack of accountability for NDIS service providers who exert their dominance over participants in this way, instead perpetuating their monopoly on the market and distorting the market's ability to preference high quality service providers. Reform is therefore necessary to change the practices of NDIS service providers initiating these proceedings. Consideration of safeguards against unsubstantiated guardianship and administration applications is needed, such as requiring NDIS service providers to take an additional step before submitting an application to the relevant state or territory tribunal, for example liaising with the NDIA or NDIS Quality and Safeguards Commission. Measures to hold service providers to account for making unsubstantiated applications should also be considered, such as penalty notices. At a minimum, the NDIS Quality and Safeguards Commission must collect relevant data, for example, the number of applications for guardianship and administration made per NDIS service provider, whether the applications are substantiated at hearing, and whether an interim order is imposed in the meantime. This data must be publicly available and will highlight the service providers requiring additional training in relation to supported decision-making practices.

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

In addition to the above feedback regarding nominee arrangements, QAI and Leadership Plus provide the following comment in relation to the proposed actions in Appendix C:

- The need for proactive information, support and guidance for participants to experience increased decision-making opportunities is welcomed. However, a ‘targeted approach for complex cohorts’ to increase their decision-making opportunities, requires further detail. What will this look like in practice?
- There is a need for consistency in the approach of Agency staff, which would indeed be facilitated by the development of a new Operational Guideline. However, this must be implemented alongside additional training for Agency staff, utilising the skills and experience of external experts on supported decision-making practices. Further, ‘improved *understanding* of support for decision-making options by our staff’ should not be a sole indicator of success. Improved *competency* in supported decision-making practices by Agency staff should also be an indicator of success, subject to appropriate evaluation processes.
- The idea of using ‘business intelligence’ using ‘data driven system alerts’ to predict when support for decision-making is potentially needed, is concerning. Supported decision-making practices must be embedded into *all* areas of practice and in all interactions with people with disability, not only at specific life stage transitions. It is an individualised approach that requires human interaction and a level of skill that cannot be replicated or anticipated by computer systems.
- Having a reduced number of nominee appointments as an indicator of success may only provide a superficial measure of success. Nominee appointments may still be required for some NDIS participants. A more helpful indicator of success would be the extent to which they successfully make decisions that reflect the will and preference of the participant or build the decision-making capacity of the participant.
- The proposal to ‘introduce a formal process to identify a participant’s decision-making capacity’ is deeply concerning. The CRPD requires a presumption of capacity at all times. This must be maintained in all Agency processes. Capacity must not be assessed purely to satisfy the Agency’s curiosity or administrative processes. Capacity must only ever be assessed if it is clinically indicated, i.e., when there is reason to suspect impaired capacity, there is a need for a decision, and the appointment of a decision-maker is required in order to protect the person’s interests. It is not appropriate to assess capacity outside of these circumstances, and people without disability would not tolerate such routine evaluation of their legal rights. To assess decision-making capacity purely owing to the presence of impairment is discriminatory against people with disability. The AHRC has said that assessing capacity should not be the starting point. Rather, focus should be placed upon assessing the level of support that is needed in order to fulfil a person’s right to make decisions. Further, such a formal process will not likely reflect the reality that decision-making capacity is not a global concept but is matter specific and likely to fluctuate depending upon the presence or omission of certain environmental factors. The focus must therefore be on establishing the participants decision-support *needs*, rather than their capacity.
- The policy must incorporate measures that ensure the decision-support needs of Aboriginal and Torres Strait Islander participants are appropriately met. Further consultation with Aboriginal and Torres Strait Islander people with disability must be proactively sought in this regard.

Conclusion

QAI and Leadership Plus thank the National Disability Insurance Agency for the opportunity to contribute to this consultation process. QAI and Leadership Plus consider that the proposed Support for Decision Making policy requires further development. Whilst there is much to admire in its intentions, it remains short on detail and open to corruption in the process of execution. QAI and Leadership Plus therefore strongly recommend that the ideas are fleshed out and subject to further consultation prior to adoption and implementation. QAI and Leadership Plus are happy to provide further information or clarification of any of the matters raised in this submission upon request.

Appendix A

These client interviews were conducted with existing and past clients of the Decision Support Pilot Project funded by DSS. Some have been able to move on from the service and utilise some decision-making support from other contacts and service providers, others have been unable to build their capability in this way and have remained with the service from the early stages of the pilot.

They all found the questions challenging, most needing further explanation and examples, some being unable to work with abstract concepts; having memory difficulties to draw examples from; or challenges with expression. Some found it difficult to separate the service that they have received, from the abstract supported decision-making policy proposed in the consultation paper.

All sentences are in the client's own words, except on occasion where the client could not find the word they needed and some words were offered as an option to choose by the person interviewing. This would have been on less than 6 occasions. Interviewing on the phone was difficult but there were no other choices with the Covid 19 lockdowns and restrictions. Using some multi choice options, pictures, and other resources to assist clients with expressing their views would have been helpful and, under normal circumstances, could have included more people's views.

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

"Listening to what we have to say and what is important to us is how you can help people to make decisions."

"Make Sure I can understand the information given."

"Provide support, have more contact with people."

"Call me and speak to me. If they don't speak to me how can I make a choice?"

"Making sure I have the information and that I understand the information given to me. The NDIS need to contact me, "the faceless people". I haven't heard from the NDIS in over a year."

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

"My decision supporter is honest and doesn't tell lies and they stick with me always. They are the only person who ever rings me – I don't have anybody else to ask anything about. My life is better now than it was because my decision supporter has helped me."

"The decision support service that I have received has been very helpful to me with the NDIS process."

"The best people to help you to make decisions are people who get to know you well. People who listen and understand me and have my interests at heart are the best people. They are people who are doing the job for me, to help me along. They are people who know what my interests are. They are people who I feel comfortable with and know well; people like my supporters and workers who I can trust."

"Advocates, my support worker and support coordinator. It's good to have help."

"My decision supporter. My support worker. The people that I trust."

What should they do to help with decision-making?

"They need to explore options and find out what's important to you. Essentially, not only do I not understand what's available or anything about what options I have, but I feel I am going in completely blind."

"They should listen to you and understand what's important to you and they should take things slowly."

"Talk to me, explain it to me, show me. Ask me what I want, call me regularly."

"Having the same person to talk to, because I have trust and they know me."

"To continue to ask questions and give me information to form my opinions."

How can they get better at helping?

"It's important to build a good relationship. My decision supporter calls me every week to talk to me. She knows me well."

"With the service that I received I never felt that I ever needed anything extra, everything was covered and always discussed in a way that I could understand."

"I think my supporters are on the right path."

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.

"The right people are people who can listen well and can understand the person's needs."

"For the right people to help, they need knowledge and skills of the topic – they just need to know the relevant areas."

"Ask me if the right people are helping me. Ask me things like how regularly we speak, if they ask me things and if I trust them."

"By asking me if they are the right people."

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

"I think I can make decisions myself but then sometimes I want to talk to somebody about it, somebody to hear about what I think. They can prompt me to think about other things and about whether it's a good decision. Often I can make my own decisions but if I need help I only have you that I come to- I have only you. My lifestyle is too limited and I have very limited opportunities to talk to anyone

(Some of this has been caused by Covid restrictions and a move from a known community to a different region, living in a facility that doesn't allow much choice or skill building/self-reliance, and currently, some inaction on the part of a support coordinator)

"For example, the art tutor who helps me needs to know different things from the person who takes me shopping."

"Its' important for people to know me and my rights."

"They should know me and to know my rights."

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

"I can't remember" (client who has quite significant memory challenges)

"For me all of the decisions that I made throughout the process of the NDIS were lots of big decisions – things like should I apply for it? What goals are important to me? What support do I want? Have I got enough funding? And what else do I need? What worked well? Well the answer to that is me being helped to understand what was happening and also what wasn't happening that should've been happening. Also my parents don't have my disabilities but they can't understand the NDIS- that could be better."

"That's too hard a question."

"I am talking about moving house. My Decision Supporter and my support worker are helping me. They talk about it regularly and give me information that I can understand. They go with the flow and allow me to change my mind. They give me time to think about, I don't get rushed or pushed to make a decision."

"My advocate helped me to decide if I need a new lawyer."

"No one told me what to do, they gave me options and gave me the information so that I could understand. I have a relationship with them and they know me."

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

"Before I lived in my current house I had a lot more people in my community (lived in a boarding house) and I could ask different people about things and to help me with decisions especially people in my church but now I don't have anybody to ask only my decision supporter. I am much more isolated now although other things in my life are better. It's better when I have more people to ask because I can spread out the help I need amongst them rather than having to call my decision supporter all the time. Sometimes I don't call her because I worry that she's busy and I don't want to bother her again."

"I need someone to give me the information. Time to think about things and be flexible."

"Give us the information to understand our plans. I can't make a decision if I don't understand."

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

"Different people have different needs – everyone does."

"There are different things to consider for people with different disabilities. For example, my disabilities make me too tired and exhausted, stressed and overwhelmed on occasions. On these occasions it makes it hard to

focus and it's difficult to work through information. You need someone who is sensitive to how you are feeling on the day and whether or not you're in a place to make any decisions."

"Different areas for different people."

"Everyone is different."

"Some people can't speak English. Changing how you work with people depending on their disabilities."

How can we help reduce conflict of interest?

"Having someone independent to help me."

"Working with people who do not get money from the NDIS."

How can we help reduce undue influence?

"This was my situation and I was able to speak up about this to my decision supporter. I would encourage a person to speak up about their choices and make that person aware of the people who might not agree with their views and to respect their wish not to have them included in some of the meetings."

"Having people help me to make decisions who have no reason to influence. Having someone regularly check things like plan nominee."

"By having someone I trust who I could tell."

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

"Do I have any concerns around people with disability making their own decisions? Well not really."

"I think it's a good thing people with disability being more involved in making decisions for themselves but with help, yes, definitely with help."

"It can be hard for me to make a choice, sometimes I need help. The right help needs to be available."

"They should have more control."

"The right help needs to be more available to people with disability."

"It is WRONG to automatically think that a person's family are they right people to help them make decisions."

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

"Based on my own experience with my decision supporter, no there isn't anything else."

“No there’s nothing missing.”

“Get more help for people to make choices. Talk to them about how they feel about it.”

“It’s important for people to know that people with disabilities can make their own decisions.”

“It feels good to make your own decisions. I know more about things and myself.”