

Submission to NDIA

Consultation Paper –

Supporting you to make your

own decisions (NDIS)



PWdWA is the lead member based disability advocacy organisation representing the rights, needs and equity of all Western Australians with disabilities via individual and systemic advocacy. PWdWA is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

WAI S is a niche, member-based, organisation. WAI S support people, families and services providers to understand, design and develop supports and services that are individualised and self-directed. Through individual and service provider memberships WAI S seeks to provide strategic advice to Government.

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People with disabilities WA (PWdWA)

Since 1981 PWdWA has been the lead member based disability advocacy organisation representing the rights, needs, and equity of all Western Australians with a disability via individual and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disabilities and aims to empower the voices of all people with disabilities in Western Australia.

PWdWA receives both state and federal funding to provide advocacy around issues experienced by the community concerning the National Disability Insurance Scheme (NDIS). In particular we are funded by the Department of Social Services to provide support with NDIS Appeals.

WA's Individualised Services (WAIIS)

Western Australia's Individualised Services (WAIIS) is a member-based community organisation working in partnership with people, families, service providers and government agencies to promote and advance individualised, self-directed supports and services for people living with disability, including psychosocial disability.

Since our inception in 2010, we have evolved to become thought leaders in this space, providing comprehensive, intentional support with integrity, passion and authenticity at our core. By leveraging our extensive local, state, and international network, we seek to lead, influence, innovate and inform to create meaningful and lasting change, supporting people to build capacity and live their lives on their own terms.

Unlike any other organisation, we partner and work with all sector stakeholders, as well as providing vital links, ensuring that disability services respond to the unique needs of people. We work to ensure that people can access and navigate the services and the sector to achieve their goals.

WAIIS is the only organisation that has a specific focus and purview of supporting and developing the capacity of people, families, service providers, Local Co-ordinators and government, specifically in the area of individualised, self-directed supports and services.

Introduction

People's access to adequate, appropriate, responsive and individualised supports funded under the NDIS to support them to live a good life is an extremely important aspect of both PWdWA's and WAI's work at both a systemic and individual level. Support for decision making has consistently been an area of our work where policy and practice of the NDIS can and should improve.

We recognise the development and implementation of the proposed policy as an expression of the NDIS Act's commitment to strengthening the upholding of the human rights of people with disability. This is a step towards upholding the Australian government's obligation to 'take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.'¹

WAI and PWdWA acknowledge and concur with the issues identified by the NDIA in the consultation paper. We are grateful for the opportunity to highlight additional issues experienced through our work, and to provide feedback on the NDIS Proposed Support for Decision Making Policy (the proposed policy).

The recommendations made in this submission are based on the experiences of people with disability, their families and carers as well as advocates and advisors who provide information and support to people. They are underpinned by the provisions in the UNCRPD, and best-practice models of supported decision making.

Summary of Recommendations

We have made a number of recommendations we strongly encourage the NDIA to adopt. In implementing these recommendations the NDIA must ensure adequate funding and resources are allocated to ensure their success.

Recommendation 1

Amend the *NDIS Act 2013* to ensure that all people with disabilities have the right to

¹ United Nations CRPD Article 12

enjoy legal capacity on equal basis with others, including the right to exercise choice and control

Recommendation 2

Strengthen the human rights basis of the proposed policy to ensure its goal and outcome is supporting people with disabilities to enact their human rights including the unqualified right to exercise legal capacity to make decisions

Recommendation 3

Provide clear definitions of the terms *individual decision making capacity* and *decision making capability*

Recommendation 4

NDIA works with people with disability, their decision supporters and people who are responsible for medically assessing capacity to determine what the process to assess and record decision making capacity should look like. This should include acknowledgement that capacity may fluctuate along with the need for support for decision making.

Recommendation 5

Robust internal policies and guidelines must be implemented so that NDIA and Partner staff do not recommend or make applications for Guardianship and/or Administration Orders unless clear evidence and rationale are available, including that it is a last resort. In this regard, mental capacity is not a sufficient rationale for recommending an application.

Recommendation 6

We recommend the NDIS proposed policy provides for the five elements of support in the WaiS Decision Making Possibilities (DMP) practice framework, to decision makers and their network of decision supporters.

We recommend that information about each of the elements of the DMP supported decision making model be developed in accessible formats to assist decision makers.

Recommendation 7

The proposed policy needs to separate the concept of capacity from good, rational

decision making or it risks perpetuating actions and policies which restrict the rights of people with disabilities to make their own decisions.

Recommendation 8

NDIA must ensure that persons, including those with appointed decision-makers, are always involved in decision making using a capacity building approach. This includes coming to the required agreements with state-based substitute-decision making authorities to ensure this occurs.

Recommendation 9

Replace the current nominee arrangements to allow participants to nominate decision supporters. This should include clear guidelines around the role, responsibilities and duties of decision supporters.

Participants should have the sole authority to appoint or revoke a decision making supporter, with the ability to specify the limitations of that support, retaining ultimate decision making authority.

Third party decisions should only be made where a person's will and preferences cannot be determined even after significant efforts (including through the provision of support). The best interpretation of will and preferences should form the basis of decisions that need to be made.

Recommendation 10

The NDIA should clearly define the concepts of conflict of interest, bias and undue influence and develop policies and guidelines to manage these issues based on best practice, including the use of independent facilitation.

Recommendation 11

The NDIA must commit to co-designing guidelines for funding reasonable and necessary supported decision making within a person's plan not only to ensure those who need it receive it, but also so that NDIA decision making is transparent and consistent.

Recommendation 12

Amend the Goal of the proposed policy to:

Support people with disabilities to enact their human rights including exercising the legal capacity to make decisions

Enable people with disabilities to build capability to direct their own lives, with the right support to do so

Recommendation 13

Amend the Roles and Responsibilities in Appendix B to “Rights and Responsibilities”. This would better reflect a rights based approach and give more weight to the statements e.g. Rights of the Participants, Responsibilities of the NDIA

Human Rights as Policy Foundations

Human rights must be central to any policy decisions or directions undertaken by the NDIA. This is enshrined in the foundations of the NDIS Act 2013 which states the Act will give effect to Australia’s obligations under the Convention on the Rights of Persons with Disabilities (UNCRPD)². The consultation paper briefly touches on human rights and legislative considerations but we believe not enough emphasis is placed on ensuring outcomes of the proposed policy promote the human rights of people with a disability.

The consultation notes the specific guiding principles in the Act relevant to decision making:

- People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports. (Section 4(4))
- People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity. (Section 4(8))
- People with disability should be involved in decision making processes that affect them, and where possible make decisions for themselves (Section 5(a))

² NDIS Act 2013, Part 2, 3(1)(a,c,e)

These principles however, must always be considered under the broader context of the UNCRPD. In the case of the proposed policy we believe it is critical that the NDIA consider how the policy contributes more broadly towards Australia's obligations under Article 5 and Article 12 of the UNCRPD:

- Article 5 Non Discrimination: to remove a person's right on the basis of a disability is to discriminate against them on the basis of that disability
- Article 12 Equal Recognition before the Law: grants people with a disability inalienable rights to legal capacity on an equal basis with others.

Article 12 does not require a person to have mental capacity in order to have legal capacity and asserts that these are two distinct concepts under the UNCRPD. Under Article 12 a person's mental capacity cannot be used as a means to deny legal capacity. From this perspective, supported decision making is about legally recognising the support offered, not by just legitimising the role of the supporter, but by formally acknowledging that the support offered changes the person's capacity. This is because supported decision making redefines capacity as interdependent.³

The right of people who don't use words or speech in typical ways for their age and culture to make decisions has often been assumed to be non-existent⁴. A supported

³ Bach, M., & Kerzner, L. (2010). *A new paradigm for protecting autonomy and the right to legal capacity* (Report prepared for the Law Commission of Ontario) Retrieved from <http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>

Browning, M., Bigby, C., & Douglas, J. (2014). Supported decision-making: Understanding how its conceptual link to legal capacity is influencing the development of practice. *Research and Practice in Intellectual and Developmental Disabilities, 1*(1), 34-45. doi:10.1080/23297018.2014.902726

Series, L. (2015). Relationships, autonomy and legal capacity: Mental capacity and support paradigms. *International Journal of Law and Psychiatry, 40*(1), 80-91. doi:10.1016/j.ijlp.2015.04.010

Watson, J. (2016a). The right to supported decision-making for people rarely heard (Doctoral dissertation). Retrieved from https://www.researchgate.net/profile/Joanne_Watson/publication/258997358_Thesis_The_right_to_supported_decision-making_for_people_rarely_heard/links/5751420a08ae17e65ec149cf.pdf

⁴ Bach, M., & Kerzner, L. (2010). *A new paradigm for protecting autonomy and the right to legal capacity* (Report prepared for the Law Commission of Ontario) Retrieved from <http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>

decision making approach starts from an assumption that the building blocks of decision making capability can be established with and around a decision maker.

The United Nations Committee on the Rights of Persons with Disabilities (CRPD) calls for substitute decision making regimes (that amount to discrimination on the basis of disability) to be replaced with supported decision making. To this end, the CRPD states that support with decision making must be made available to everyone and that the government has the responsibility for facilitating the creation and availability of this support in the community.

We acknowledge the NDIS sits within the broader legal and political landscape where issues around legal capacity, mental capacity and supported decision making are playing out. There is currently no consistent approach within Australia to legal capacity. Many States and Territories still have best interest substitute-decision making systems in place which are at clear odds with the intent of Article 12.⁵ Additionally, government support for people with disabilities goes beyond just the NDIS. There is an expectation that all levels of government (federal, state, and local) provide services that are accessible to people with disability, consistent with a human rights commitment. All these jurisdictions need a legal supported decision making framework, for example, to assist people with disability to make decisions related to health, justice, education, or engagement with local government.

A society-wide cultural change is needed to embed a supported decision making approach to upholding the right of people with disability to have a say in the decisions that impact their life. There is currently an opportunity to learn from other countries, such as Austria, which have developed a whole-of-government approach to supported decision making. The NDIS can set the precedent within Australia by developing a best practice approach to supported decision making which mainstream government services, funded human services and the private sector could adopt and adapt to strengthen the extent to which the UNCRPD Article 12 is upheld in this country. More broadly this means reviewing the NDIS Act 2013 to remove qualifiers of legal capacity that currently exist in the legislation.⁶

⁵ The Committee on the Rights of Persons with Disabilities, *General Comment No. 1; Article 12: equal recognition before the law*, 11th sess, UN Doc CRPD/C/GC/1/, 19 May 2014, [27].

⁶

Recommendation 1

Amend the *NDIS Act 2013* to ensure that all people with disabilities have the right to enjoy legal capacity on equal basis with others, including the right to exercise choice and control

Recommendation 2

Strengthen the human rights basis of the proposed policy to ensure its goal and outcome is supporting people with disabilities to enact their human rights including the unqualified right to exercise legal capacity to make decisions

Individual Capacity vs Decision Making

Capability

Individual decision making capacity has been the basis for justifying informal and formal substitute decision making arrangements. However, decision making capability is the basis for supported decision making. It's vital that all decision supporters and decision makers understand the difference.

There is no uniform definition or standard for capacity in legislation.⁷ How capacity is defined in law has meant people with intellectual and other cognitive disabilities have had to demonstrate their autonomous, rational capacity to understand and appreciate the consequences of decisions.

Decision-making capability is an alternative way of viewing capacity based on: ability + supports and accommodations⁸. Decision making capability is a feature of the person and their supporters, which can be increased through the group knowing the person and applying a supported decision making model.

⁷ ALRC report *Equality, Capacity and Disability in Commonwealth Laws* (ALRC report 124). [alrc_124_whole_pdf_file.pdf](#)

⁸ Bach, M., & Kerzner, L. (2010). *A new paradigm for protecting autonomy and the right to legal capacity* (Report prepared for the Law Commission of Ontario) Retrieved from <http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>

With the right support and accommodations, a person's decision making capability can be increased through exploring, making and implementing decisions. An example of an accommodation is having time for a supported decision making process. People with CCAN may need significant time to receive information about a decision, weigh up the decision and communicate the decision to people who can interpret their communication. The NDIS and other support systems need to allow the time needed.

NDIA has also provided limited information on how they plan to assess and record a person's individual decision making capacity including where they sit on the decision making continuum outlined in Appendix B. There is no information on how this assessment will actually be used in practice, including in the appointment of nominees.

Recommendation 3

Provide clear definitions of the terms *individual decision making capacity* and *decision making capability*

Recommendation 4

NDIA works with people with disability, their decision supporters and people who are responsible for medically assessing capacity to determine what the process to assess and record decision making capacity should look like. This should include acknowledgement that capacity may fluctuate along with the need for support for decision making.

Additional issues relevant to Supported Decision Making

WAI S and PWdWA would like to take this opportunity to highlight how policies and directions within the NDIA are leading to the appointment of substitute decision makers in Western Australia. This issue was not specifically raised within the consultation paper but must be recognised and addressed.

Western Australia operates under a substitute decision making model where a guardian and/or administrator is granted the legal right to make decisions on another person's behalf based on their perceived best interest. It is a system at odds with the UNCRPD, which strips a person of their right to make decisions about their own life, and to have their will and preferences respected.

WAI and PWdWA have experienced a disturbing trend around the application for guardianship orders involving NDIA staff and support providers. This includes guardianship orders being recommended by NDIA staff or Support Coordinators as a matter of routine for people with intellectual, cognitive or psychosocial disability who have limited family support. Parents/family members who play a significant role in supporting the decisions of their loved one are also being strongly encouraged to apply for guardianship. Additionally, support providers in WA are known to seek guardianship orders with the intent of keeping people safe and managing conflict. It is rare for the person with a disability to be consulted when an application is made. The application process often leads to long-lasting trauma which for many is compounded by having their legal right to make decisions removed.

In many of these cases there has been no consideration of the role Support for Decision Making could have played. In some cases NDIA staff have specifically stated if a person requires a high level of support to make decisions then someone else should be making those decisions for them. Although the NDIA is not responsible for each State's and Territories approach to legal capacity, they cannot ignore the intersection between the NDIS and other systems. Without a human rights approach, which acts to minimise the occurrence of substitute decision making, the NDIS risks creating situations where people's human rights are taken away.

Recommendation 5

Robust internal policies and guidelines must be implemented so that NDIA and Partner staff do not recommend or make applications for Guardianship and/or Administration Orders unless clear evidence and rationale are available, including that it is a last resort. In this regard, mental capacity is not a sufficient rationale for recommending an application.

Feedback on Proposed Policy

Fundamentals of effective supported decision making⁹

The proposed policy needs to be informed by greater depth of practice knowledge of supported decision making. We describe below some important elements that need to be provisioned in the proposed policy.

A supported decision making process starts with the decision maker identifying who they want to invite to be their decision supporters. We generally choose with whom we will speak to about what topics when we need to make a decision. We choose a few people, perhaps on the basis of trusted relationship, and history or expectation of their respect and belief in us. This would be no different for people with disability. Decision supporters are led by the person to develop a better, shared understanding of the decision maker and how they want to live and self-direct their life.

Decision supporters need to understand, agree with, commit to and implement the spirit of the UNCRPD and supported decision making principles. They need to understand decision making capability and their part in building it with a decision maker. Their role is to help the person explore, clarify and communicate their will and preferences in relation to a specific decision opportunity¹⁰. For people with CCAN, supporter responses involve acknowledging, interpreting and acting on the person's expressions of preference¹¹ as the building blocks of their decision making¹².

Building decision making capability starts before an NDIS plan is developed. An NDIS plan should be informed by a genuine person centred planning process with a decision maker and their supporters. This is the foundation to understanding and

⁹ Questions 1, 3, 7, 9

¹⁰ Browning, M. (2018). Developing an understanding of supported decision-making practice in Canada: The experiences of people with intellectual disabilities and their supporters (Doctoral dissertation). La Trobe University, Melbourne, Australia.

¹¹ Watson, J., Wilson, E. & Haglissis, N. (2017). Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30, 1022–1034. doi:10.1111/jar.12393

¹² Watson, J., Voss, H. & Bloomer, M.J. (2019). Placing the preferences of people with profound intellectual and multiple disabilities at the center of end-of-life decision making through storytelling. *Research and Practice for Persons with Severe Disabilities*, 44(4), 267-269. Doi:10.1177/1540796919879701

acting on their expressions of will and preferences as the building blocks of their decision making. This planning process also highlights upcoming decision making opportunities. As these opportunities are explored, a decision maker may want to make changes to their NDIS plan. Decision supporters are well placed to assist them to do this.

People need to have information in a range of accessible formats including plain language, easy read and multimedia formats. People with disabilities need to be involved in the development, production and testing of these resources. Decision makers may also need specific support that's consistent with their informal or formal communication system to understand information.

The broad support needs of people with disability to make and communicate decisions are also more likely to be met if we start by addressing the support needs of people with complex communication access needs (CCAN).

In some settings people are not supported to have input to decisions which impact on them, including their support or treatment, unless they use spoken or written words to provide consent for advocacy support. The requirement for consent in this way also restricts the opportunity to bring together or get input from people who know them and their communication to support their decision making. Support systems need to validate the range of ways a person communicates their preferences and decisions in the context of decision supporters who know them.

We agree that there are different cultural needs that need to be considered for decision makers. A supported decision making process which starts with the person being supported to identify and invite their preferred decision supporters will go some way to meeting their cultural needs in the context of building decision making capability. The role of the NDIS is to respond to cultural needs whilst also upholding the person's right to exercise their legal capacity as a decision maker.

Support for decision making is a long term investment and strategy for people, families, communities and across government. The NDIS must adequately invest in building the capacity of people and their supports through their funding with a long term outlook.

Proposed SDM Practice Framework

A robust supported decision making framework can help to ensure the quality of the process. The proposed framework presents as a very linear process for supported decision making. However, decision making does not always follow a linear process. The examples given in the paper are very straightforward decisions with no complexity, for example where a person has limited decision supporters, or requires communication support, or the decision carries a level of risk. The approach appears to try and systematise everything into simple boxes when in reality decision making in real life doesn't fit a box e.g. life/stages/impact.

WA's Individualised Services is currently managing an ILC-funded supported decision making project. The Decision Making Possibilities (DMP) Practice Framework is based on research and learning from a previous WAIIS supported decision making project. It consists of five key elements of support to a decision maker and their network:

1. Network establishment and support through facilitation
2. Communication support
3. Knowledge of the person and genuine person centred planning
4. Education and training on human rights, social model of disability and supported decision making; and
5. A supported decision making model of practice.

Each of these elements work together to build the capability of people and their network of decision supporters to make decisions and determine their own lives.



Decision Making Possibilities applies the following model of supported decision making.



Recommendation 6

We recommend the NDIS proposed policy provides for the five elements of support in the WAiS Decision Making Possibilities (DMP) practice framework, to decision makers and their network of decision supporters.

We recommend that information about each of the elements of the DMP supported decision making model be developed in accessible formats to assist decision makers.

Independent/Rational/Good Decision Making¹³

We are concerned that particularly in the period of transitioning to adulthood, a paternalistic approach will be perpetuated by the NDIS, expressed through expectation of holding people with disability to a higher standard than the general community in terms of being perceived as making rational decisions. The consultation paper suggests that when trying to make decisions a person *must* weigh the positives and negatives and *needs* to think about what might happen in the future. In the general population, people's capacity is not correlated with independent, rational or 'good' decisions. Most people will make irrational decisions in their life, or decisions where they are not sure of the consequences. Experiencing those consequences is part of learning.

Decision supporters often demonstrate their bias towards keeping a person safe. We note that keeping a person safe is not the explicit goal of supported decision making. People should be free to take risks. However, the goal of building decision making capability should include exploring the question of what will it take for the person to be the safest they can be whilst taking risks.

Recommendation 7

The proposed policy needs to separate the concept of capacity from good, rational decision making or it risks perpetuating actions and policies which restrict the rights of people with disabilities to make their own decisions.

¹³ Questions 1, 3

Role of informal and formal decision makers¹⁴

Knowing a person is important to being able to assist them with making decisions. Knowing a person's history and life story correlates with intimate or very close relationships¹⁵. This level of knowledge in supporters makes them more likely to be responsive to that person, in terms of acknowledging, interpreting and acting on their expressions of preference.

Effective decision supporters have a range of beliefs, attitudes, knowledge and skills. Willingness to be in the role is a necessary but basic starting point. Decision supporters should be effective communication partners who are attuned and acknowledge, interpret and act, or facilitate action, on the person's communication. Decision supporters need attitudes of belief and expectation of building decision making capability. Decision supporter relationships should be characterised by equality, respect and trust.

Supported decision making research has pointed to the importance of decision makers and their supporters receiving education and training on a range of topics including the right of people with disability to make decisions¹⁶, their right to enjoy legal capacity on an equal basis with others¹⁷, the aim and principles of supported

¹⁴ Questions 2, 5, 6

¹⁵ Watson, J. (2016a). The right to supported decision-making for people rarely heard (Doctoral dissertation). Retrieved from https://www.researchgate.net/profile/Joanne_Watson/publication/258997358_Thesis_The_right_to_supported_decision-making_for_people_rarely_heard/links/5751420a08ae17e65ec149cf.pdf

¹⁶ Burgen, B. (2016). Reflections on the Victorian Office of the Public Advocate supported decision-making pilot project. *Research and Practice in Intellectual and Developmental Disabilities*, 3(2), 165-181. doi:10.1080/23297018.2016.1199969

¹⁷ Harding, R., & Taşciouğlu, E. (2018). Supported decision-making from theory to practice: Implementing the right to enjoy legal capacity. *Societies*, 8(2), 25-39. doi:10.3390/soc8020025

decision making¹⁸, understanding the process of decision making support¹⁹ and developing practical strategies in how to provide decision support²⁰.

Supported decision making practice evidence suggests that a formalised network facilitator role helps to ensure independence and sustainability of the process. Ideally, independent facilitation of supported decision making is in the context of a group of decision supporters.

There are limitations to the suggested formal supports in the proposed policy. The stakeholders identified should be part of the process but not driving it or leading the decision maker.

Formal decision makers within the NDIS often don't know the person, carry inherent bias from working within the system and may have a conflict of interest in terms of the decisions being made.

In relation to proposed NDIS changes to the appointment of nominees, NDIS staff, nominee applicants, supporters and decision makers need to:

- know that a legally appointed substitute decision maker is a last resort and when one is appointed, this should NOT mean the person is no longer involved in a decision making process.
- recognise that appropriate supports can reduce, or eliminate the need for substitute decision makers
- understand that decision making capacity is person-, support-, decision- and circumstance-specific
- offer ongoing support for decision making on the assumption that the person can learn and develop capacity as a decision maker.

¹⁸ James, K., & Watts, L. (2014). Understanding the lived experiences of supported decision-making in Canada: Legal capacity, decision-making and guardianship (Report commissioned by the Law Commission of Ontario). Retrieved from <https://www.lco-cdo.org/wp-content/uploads/2014/03/capacity-guardianship-commissioned-paper-ccel.pdf>

¹⁹ Browning, M. (2018). Developing an understanding of supported decision-making practice in Canada: The experiences of people with intellectual disabilities and their supporters (Doctoral dissertation). La Trobe University, Melbourne, Australia.

²⁰ Bigby, C., Whiteside, M., & Douglas, J. (2017a). Providing support for decision making to adults with intellectual disabilities: Perspectives of family members and workers in disability support services. *Journal of Intellectual and Developmental Disabilities*, 1-14. doi:10.3109/13668250.2017.1378873

The suggestion that advocacy, peer support or circle of supports can be relied on for supported decision making is unworkable on several counts:

- Advocacy services are already unable to meet the demand for their service
- Advocacy services are issues based, time-limited supports that are accessed when a person is facing a specific problem. Knowledge of a person's will and preferences is limited to the specific circumstance they are engaged around
- Whilst it is true that these supports may indirectly help to build decision making capability, this is not their reason for being. Without explicit clarity about using a supported decision making approach and relevant education, it's likely that people will not understand their roles or the process, and the potency of the approach will be diminished.

These models of support must be acknowledged, respected and given the required scope to support someone to exercise their legal capacity but cannot be expected to meet the need for decision making support. They must also be appropriately funded to ensure their availability to everyone who needs them.

We know that some people with a disability do not have people in their lives to help them work with the NDIS or to help them to develop and use their NDIS plan. For people who are isolated, there may be value in offering the opportunity and support to bring together potential decision supporters who are interested to build a relationship with the person, learn their communication, support their decision making and facilitate their connection with long term decision supporters. A relevant example is contained in the IAC Support for decision making in the NDIS, July 2019 discussion paper.

A participant who lives in a boarding house or group home and is isolated from family and friends could identify decision making as a goal in their plan, could be allocated reasonable and necessary capacity building support to build relationships and support decision making and be supported to become a member of a peer network.

The need for a values-based, supported decision making process is especially important for people whose decision support needs are complex. Formal decision supporters tend to apply black and white rules to these contexts which err towards taking away a person's right to choose. It can take a facilitated, skilful and knowledgeable group of decision supporters who know the person and who are committed to supporting both their rights and their wellbeing to navigate an effective supported decision making process.

Recommendation 8

NDIA must ensure that persons, including those with appointed decision-makers, are always involved in decision making using a capacity building approach. This includes coming to the required agreements with state-based substitute-decision making authorities to ensure this occurs.

Recommendation 9

Replace the current nominee arrangements to allow people to nominate decision supporters. This should include clear guidelines around the role, responsibilities and duties of decision supporters.

People should have the sole authority to appoint or revoke a decision making supporter, with the ability to specify the limitations of that support, retaining ultimate decision making authority.

Third party decisions should only be made where a person's will and preferences cannot be determined even after significant efforts (including through the provision of support). The best interpretation of will and preferences should form the basis of decisions that need to be made.

Conflict of interest, bias and undue influence²¹

The NDIS has an obligation to implement the proposed policy such that it 'ensures that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.' (Article 12 UNCRPD)

The proposed policy and its implementation needs to clarify and educate people about the related concepts of conflict of interest, bias and undue influence. If these are not properly understood and managed by people involved in supported decision making there is a risk to the person's human rights in that their decision may not be heard and upheld, or they may be placed at non-consensual risk.

The three may be managed differently, for example, a decision supporter who has a paid role in the person's life may need to withdraw from a specific decision making process due to conflict of interest. Bias is a broader concept. Every decision supporter brings bias to the process so they can never be entirely neutral. Their own values, experiences, goals, priorities and preferences can influence the support they provide. But the intention they have when providing support, and the strategies they take to mitigate the impact of their biases, such as trying to be as neutral as possible, non-judgmental and minimising their influence are very important.

In order for bias to be effectively managed it must become conscious and shared, otherwise it can manifest as undue influence on the decision maker's process. Independent facilitation of the process can assist with minimising the impact of bias and undue influence on a decision maker. It should also ensure the person feels safe in the process of making a decision.

²¹ Questions 10, 11

Undue influence can manifest as a range of decision supporter tones of engagement, for example a patronising, cloying tone which leads a decision maker to want to please others with their decision, or a paternalistic, controlling tone which leads a decision maker to not want to distress or anger others with their decision. Undue influence may occur when the decision being made has the potential to negatively impact on a decision supporter.

Inherently NDIA and support staff have a level of undue influence due to the uneven power dynamics they hold. There is also a conflict of interest as they are both facilitating support for the person but responsible to others for how that support is provided.

A group of people who know the person and are committed to building their decision making capability can protect the person from the negative impacts of conflict of interest, bias and undue influence.

Recommendation 10

The NDIA should clearly define the concepts of conflict of interest, bias and undue influence and develop policies and guidelines to manage these issues based on best practice, including the use of independent facilitation.

Funding SDM for individuals vs increasing sector and supporter capabilities²²

We are concerned that people are not supported to have a breadth of experiences which then lead to decision opportunities. This is especially relevant for people who are isolated or who have lived in institutional settings. Genuine person centred planning leads to a broader range of experiences and choices which is an essential basis for a person to exercise their legal capacity. This element of support is currently missing and not funded for many people. The NDIS needs to offer funding for the support elements which contribute to building decision making capability

²² Questions 1, 4, 8

which is a long term investment (see Decision Making Possibilities Practice Framework). We are concerned about the NDIS perpetuating broader low societal expectations about people's adult lives and the extent to which they will include typical experiences such as contribution, work and creating a home, by not fully supporting people to exercise their legal capacity to direct their lives.

We are concerned that the proposed policy does not include a clear commitment to providing NDIS funding for people to build decision making capability. Individualised funded support must be made available if the stated goals are to be achieved.

The NDIS investment in training, education, and support related to supported decision making, including genuine person centred planning and communication is missing for most people. It's important that all stakeholders are educated about how people typically make decisions and for this knowledge to be applied in a supported decision making context. However, the supported decision making context for people with disability needs more intention and structure than is typical for the broader community. Without education, intention and structure, the risk is that decision supporters won't understand their role, and the quality of the process and outcome is reduced.

We are concerned about the proposed policy assumption that capability will be built and therefore support for decision making funding will reduce over time. The NDIA cannot take an approach that an investment will reduce or remove the ongoing cost of support for decision making for all participants. The elements and practice of effective decision making support may be developed over time so that the decision maker's capability is more responsive in a shorter time frame. However, capability may only be built with the right formal and/or informal support in place and in many cases the need for support with decision making will fluctuate, for example, for people with episodic psychosocial disability. Practice evidence indicates that without external facilitation, networks and circles of support tend to fragment in a two-to-three year timeframe. Therefore, the default approach must be to provide maintenance support for decision making capability as needed.

Sitting alongside this is the intersection between the NDIS and other mainstream services where a person may require support for decision making in order to exercise their legal right to make decisions. The consultation paper does not address

the need for people to receive support for decision making outside of just their NDIS plans and supports. For example, this may include medical treatment decisions or financial decisions. It is not clear if the NDIA has considered how these supports will interact. It has the potential to leave substantial gaps in the decision making support that people may need across the whole breadth of their lives.

Recommendation 11

The NDIA must commit to co-designing guidelines for funding reasonable and necessary supported decision making within a person's plan not only to ensure those who need it receive it, but also so that NDIA decision making is transparent and consistent.

Other feedback

We believe the proposed Key Principles and Goals in the proposed policy could be stronger. The current statements are too passive and do not place enough emphasis on human rights outcomes.

Recommendation 12

Amend the Goal of the proposed policy to:

Support people with disabilities to enact their human rights including exercising the legal capacity to make decisions

Enable people with disabilities to build capability to direct their own lives, with the right support to do so

Recommendation 13

Amend the Roles and Responsibilities in Appendix B to “Rights and Responsibilities”. This would better reflect a rights based approach and give more weight to the statements e.g. Rights of the Participants, Responsibilities of the NDIA