

Independent Advisory Council of the NDIS

Support for decision making in the NDIS

July 2019

Table of Contents

Purpose	3
Context	3
<i>In law</i>	3
<i>In practice</i>	4
<i>In the NDIS</i>	5
<i>In practice in the NDIS</i>	5
Understanding support for decision making	7
<i>Distinguishing between choice and decision</i>	7
<i>Nature of support for decision making</i>	7
<i>Source of support for decision making</i>	8
<i>Steps in supporting decision making</i>	10
<i>Emerging knowledge</i>	11
Support for Decision making Framework	12
<i>Strategies to strengthen decision support</i>	13
<i>Support for decision making for participants with intellectual disability and cognitive impairment across the lifespan</i>	14
<i>Support for decision making for participants with psychosocial disability</i>	19
<i>Support for decision making in the NDIS</i>	22
Risks	28
<i>Participants are not supported to make decisions</i>	28
<i>Participants in need of decision support are not identified early</i>	28
Mitigation strategies.....	28
<i>The quality of decision support remains poor</i>	29
Mitigation strategies.....	29
The way forward	29
References	31

Purpose

The purpose of this paper is to develop an understanding of the concept of support for decision making in the NDIS. The paper will provide the basis of advice to the NDIA Board in relation to the development and implementation of a consistent approach for support for decision making that meets the Scheme's obligations and aspirations to provide real choice for people with disability.

Context

Supported decision making is the term used internationally and across Australia to describe the process of providing support to people to make decisions and remain in control of their lives. Supported decision making starts from the premise that everyone has the right to participate in decision making and everyone draws on some support at some time to make some decisions.

In law

The right to make decisions is enshrined in United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in which Article 3 accords inherent dignity, individual autonomy including the freedom to make one's own choices and Article 12 accords persons with disabilities with legal capacity on an equal basis as others in all aspects of life. In signing the UNCRPD, the Australian Government committed to develop "appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (UNCRPD 2006).

In examining the implications of Article 12, the Australian Law Reform Commission¹ identified four decision making principles to reflect the paradigm shift toward supported decision making in Commonwealth laws. The principles are:

Principle 1: The equal right to make decisions: All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Support: Persons who require support in decision making must be provided with access to support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will preferences and rights: The will, preferences and rights of persons who may require decision making support must direct decisions that affect their lives.

Principle 4: Safeguards: 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.

S3(1)(a) of the *National Disability Insurance Scheme Act, 2013* explicitly gives effect to Australia's obligations under the UNCRPD.

¹ Australian Law Reform Commission, (2014), *Equality, capacity and disability in Commonwealth law*

In some jurisdictions, people with psychosocial disability can draw on requirements for support for decision making from Mental Health Acts which provide requirements in relation to support for decisions about assessment, treatment and recovery via advance statements,² nominated persons,³ second psychiatric opinions⁴ and advocacy.

In practice

Each individual comes with a legacy of choice or denial of choice experienced in childhood and adulthood. For many individuals, this has resulted in disempowerment or loss of voice which prevents them from exercising choice.⁵ Mental Health Australia notes that access to decision making may have less to do with a person's functional capacity to decide, than with the values and attitudes of those who share their lives.⁶

Decision making for most people in need of decision support continues to rely on informal arrangements where decisions are made by others, often in the person's 'best interests' and may not consider or include the person's will and preferences or opportunities to try new experiences.

For some NDIS participants, the right to make decisions has been removed under guardianship with jurisdictions continuing to use 'best interest' as the basis for decision making.

A very significant proportion of disability services across Australia and in many other countries are predicated on pre UNCRPD models in which people without disability made decisions and exercised choice for people with disability "in their best interest". Consequently, a significant proportion of pre-existing services now purchased by participants have operations, structures and cultures predicated on decisions made by others based on the best interests of the person. This is in contrast to the principles described above.

The increased protections in law for people with psychosocial disability are often reflected in Practice Guidelines⁷ that encourage mental health practitioners to incorporate supported decision making into practice in clinical, non-government and community support services to meet clinical, ethical and legal obligations. A 2010

² Advanced statements allow people to set out their treatment preferences should they become unwell and receive compulsory treatment for mental health challenges.

³ A person may be able to nominate another person to support him or her represent his or her interests in relation to mental health treatment. For example, in Victoria, a nominated person must be consulted about treatment (*Mental Health Act 2014* s23(c) but cannot make decisions on behalf of the person being treated.

⁴ Any person who is subject to a Temporary treatment Order or Treatment Order in Victoria, or is a security or forensic patient, can request a second opinion. This may enable people to participate in decisions about treatment by promoting discussion between the authorised psychiatrist, the treating team, the person, family and carers.

⁵ Wilson, E., Campain, R., Pollock, S., Brophy, L. & Stratford, A. (2018) *Understanding people with psychosocial disability as choice-makers in the context of the NDIS*, Burwood, Deakin p vii

⁶ Mental Health Australia, ADACAS (2016) *Supported decision making, psychosocial disability and the NDIS*, p18
Accessed

https://mhaustralia.org/sites/default/files/docs/supported_decision_making_psychosocial_disability_and_the_ndis.pdf
16 February 2019

⁷ Brophy, L., McSherry, B., Kokanovic, R., Moeller-Saxone, K., Herrman, H., Guidelines for supported decision making in mental health services Accessed at <http://healthtalkaustralia.org/wp-content/uploads/2017/09/Guidelines-for-Supported-Decision-making-in-Mental-Health-Services.pdf> 16 February 2019

report by the Department of Health⁸ suggested that the mental health sector was beginning to interpret support for decision making as a skill set or professional capability with support for decision making frameworks used as a tool to explore and document decisions that balance dignity of risk and duty of care.

In the NDIS

Choice is a fundamental element of the NDIS, with support for decision making inferred in the NDIS responsibility “*to enable people to exercise choice and control in the pursuit of their goals and in the planning and delivery of their supports*” (Object 3(1)(e)). Support for decision making is further operationalised in the General Principles of s4 of the NDIS Act, especially Principle 4 in reference to support to take reasonable risks, Principle 8 in reference to ability to determine own best interests and engage as partners in decisions and Principle 9 in reference to dealings and communications with the Agency.

The emphasis on the rights of people with disability to make their own decisions and exercise choice and control under the NDIS is a genuine paradigm shift.

It is important to stress however, that decision making arrangements in the NDIS also incorporate substitute decision making by nominees who can be appointed where it is not possible to support, and build the capacity of participants to make their own decisions for the purpose for the NDIS.⁹ The NDIS practice in relation to nominees lacks clarity. 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.

Participants aged over 15 with disabilities that impact on their decision making capacity represent over 40%¹⁰ of all NDIS participants. The immediate challenge for the NDIS is to ensure that participants have support to enable them to participate in decisions in preplanning, planning and plan implementation as well as in their day-to-day lives. Support for decision making is one of a suite of strategies required to strengthen demand and empower participants to become informed consumers who challenge or walk away from service offerings that will not deliver outcomes promised by the NDIS.

In practice in the NDIS

The gap between the protections theoretically afforded by legislation, practice guidelines and role descriptions and experience on the ground, especially in the emerging market place of the NDIS is an underlying theme of support for decision making for all participants.

⁸ Department of Health (2010), *Principle of recovery oriented mental health practice*, Australian Government Mental Health website. Accessed <http://www.health.gov.au/internet/publications/publishing.nsf/Content%20mental-pubs-i-nongov-toc~mental-pubs-i-nongov-pri> 18 February 2019

⁹ NDIS Nominee Rules R3.1

¹⁰ At 30 Sept 2018, 62% of participants or 123,086 people with an active plan were aged over 15 years. Of participants over 15 years, 68% or 83,869 have disabilities that impact on decision making (specifically autism, intellectual disability, psychosocial disability, developmental delay, global developmental delay and acquired brain injury) Hence the % of participants over 15 with a disability that impacts on their decision making is 42.16%.

Research by Kokanovic ¹¹ and Wilson & Pollock ¹² suggests that there is a long way to go before people with psychosocial disability feel supported in their decision making. Kokanovic documents concerns with support for decision making arising from characteristics of people experiencing severe mental health problems, problems in practice and features of the mental health system (especially features that reinforce the expertise of the health professional) and Wilson & Pollock describing the 'labour of choice' of the NDIS, documenting challenges arising from the significant number of choices and decisions required by the NDIS.

For participants who lack informal support, especially participants living in SDA, advocates have provided valuable support for decision making for those fortunate enough to have an advocate. Advocates report however, that NDIA practice seems to prefer decision support from the SIL provider rather than an independent advocate. Examples reported by advocacy organisations include the NDIA:

- discouraging independent support for decision making claiming that “the person can talk”, “there wasn’t enough time for that”, “the House Supervisor knows them really well” or “they will get a typical package anyway so it doesn’t matter”;
- holding planning meetings without the participant present on advice from SIL provider as the key informant;
- allowing the SIL provider to choose Support Coordination (including from their own organisation) on behalf of participants rather than deferring to an independent advocate;
- listing the SIL provider as an 'Authorised Contact' on the participant's file even though the SIL provider does not have the express consent of the participant while prohibiting an advocate from being listed as the 'Authorised Contact';
- funding Support Coordination at a level that does not enable the development of long-term support for decision making mechanisms, even where the person has severe intellectual disability and will not develop capacity to represent themselves in interactions with the NDIA; and
- refusing requests for reasonable and necessary support to build enduring relationships in the local neighbourhood and community.

The recent practice of preventing advocates from seeking a plan review for participants who lack informal support has barred their only support for decision making and deprived them of their right to a review under s48 of the NDIS Act. Legal advice from community-based advocacy organisations suggests this is arbitrary, discriminatory and prejudicial to many participants and contrary to the spirit of the NDIS Act.

¹¹ Kokanovic, R., Brophy, L., McSherry, B., Hill, N., Johnston-Ataata, K., Moeller-Saxone, K., & Hermann, H., (2017) *Options for supported decision making to enhance recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melbourne

¹² Wilson, E., Campaign, R., Pollock, S., Brophy, L. & Stratford, A. (2018) *Understanding people with psychosocial disability as choice-makers in the context of the NDIS*, Burwood, Deakin pviii

Understanding support for decision making

Distinguishing between choice and decision

Choice is a fundamental value of the NDIS with the intention of enabling participants to have opportunities to select options based on beliefs and an estimation of where the choice will lead. A decision, on the other hand, is an analytic method to eliminate options through, ideally, a thoughtful, thorough process that begins with choices and opportunities and considers past experiences.

The NDIS offers participants an unprecedented number of choices but participant ability to take advantage of these opportunities will be impacted on by their pre-disposition around choice, the nature of their disability, their life circumstances and their mental health. It is therefore important to acknowledge that support for decision making is a highly skilled endeavour if it is to approach the expectation of a ‘thorough process that begins with choices and opportunities and considers past experiences’.

Nature of support for decision making

Decision making can be seen as a continuum. At one end is autonomous decision making where the person makes their own decisions and at the other end is substitute decision making where a person’s right to make decisions is removed via a legally constituted tribunal, service provider or by well-meaning family.

Supported decision making seeks to bridge the current chasm, acknowledging the uneven playing field between participants in need of decision-support and representatives of services and systems. Supported decision making draws on a support paradigm that presumes everyone has some capacity to exercise choice and make decisions for themselves when given the right support; acknowledges that the capacity to make decisions grows and develops, so making decisions over small things provides practice to enable bigger decisions to be made; that not all decisions are of the same consequence; and that capacity to make decisions is related to the nature of the decision and the nature of support. Ultimately, support for decision making is based on the premise that sufficient and effective decision making support compensates for difficulties in decision making.

A key feature of supported decision making relates to the change from decisions made in the person’s best interests to decisions that reflect then person’s will and preferences.¹³

The term ‘supported decision making’ describes both practice and legal frameworks. This paper uses the term ‘support for decision making’ to refer to those elements of

¹³ “Best interest is not a safeguard that complies with Article 12 for adults; support to express their will and preferences is seen as an important form of support for decision making for participants who use non-verbal forms of communication. General Comment No. 1 of Article 12 Accessed at <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx> 9 November 2018

supported decision making that can be implemented now within the current Australian legal context.¹⁴

The concept of support for decision making is not well understood.

There are two key elements of support for decision making. The first element relates to strategies to build the capacity of the person with disability to make or contribute to the making of decisions. The second element relates to strategies that increase the capacity of 'informal supporters' (i.e. family, friends and service workers) to provide the encouragement, opportunity and practice that contribute to enabling the person to make decisions and make it more likely that the decisions reached reflect the 'right' decisions. For a small but significant group of people with disability who have no one in their lives effectively able to support them to make decisions, the supporters must be intentionally recruited and assisted to have the respect, skills and insights necessary to support the person to make or contribute to the making of decisions.

Source of support for decision making

Research by Kokanovic et al¹⁵ reminds us of the systemic responsibility for sourcing support for decision making because so many of the enablers and barriers exist in features of the service system.

Conditions for empowered decision making can be found at the level of:

- policy and regulation (i.e. the infrastructure to support participants to make their own decisions including legal and rights-based mechanisms¹⁶ and practice guidance¹⁷ and to monitor its effectiveness)
- funded and informal supports (interpersonal skills of providers, the value placed on peer support, management and leadership of services)¹⁸ and the skill, experience and support provided to informal decision supporters; and
- the individual including the capacity building and peer strategies to empower people.

Support for decision making relies on the supporter being someone the person with disability knows and trusts, someone who respects their opinions and preferences and has the skills to encourage and extend the person's capacity and contribution to making decisions. The supporter needs to understand who the person is, the important people in their life, what their life is like now and the extent to which their current life

¹⁴ The Australian legal context is changing with a number of States and Territories examining the way in which their laws can be made consistent with Article 12 of the UNCRPD. For example, in Victoria, the *Guardianship and Administration Bill 2018* includes roles for 'supportive guardianship' and 'supportive administration'. In its 2018 review of the Guardianship Act, the NSW Law Reform Commission recommended that an *Assisted Decision making Act* replace the *Guardianship Act*.

¹⁵ Kokanovic, R et al (2017)

¹⁶ Kokanovic, R et al (2017) p53 – e.g. advance care directives, nominated persons, rights information and awareness, advocacy and second opinions

¹⁷ Kokanovic, R et al (2017) p50 including people not feeling (or being) heard, lack of awareness about rights and supported decision making, lack of collaboration, lack of person centred perspective, lack of respect and power differentials

¹⁸ Kokanovic, R et al (2017) p55 e.g. staff supervision and support, training, knowing yourself as a worker, needing to recognise and support change, resourcing and education

matches who the person is ¹⁹. Real understanding takes insight, time and empathy. It requires knowing the person well.

Ideally the supporter has minimal conflict of interest with the person whose decisions they are supporting. Families and close friends are often the natural choice but it is important they be helped to acknowledge possible conflicts. ²⁰ Having contact with an ILC service that runs seminars on support for decision making and helps participants to identify and manage possible conflicts of interest may mitigate the risk of such conflicts impacting negatively on decision making support.

Research by Mental Health Australia ²¹ shows some decision-makers with psychosocial disability have expressed preference for independent decision support that is not freely given but purchased from a skilled expert. This was complemented by a strong willingness on the part of professionals in the mental health sector to take up a role in decision support ²², reinforcing the view that an NDIS approach to support for decision making must be responsive to the unique circumstances and preferences of each participant.

The NDIA expects LACs, planners and Support Coordinators to provide support for decision making. This expectation is often not fulfilled. The lack of trust and familiarity in the relationships means that participants often do not actually make decisions that reflect their will and preferences and participants seldom have increased capacity to make decisions as a result of the interaction.

For example, support for decision making by an LAC or NDIA planner is limited by their superficial knowledge of the participant, their focus on high level NDIS decisions and for the planner, their responsibility to determine funding levels.

Despite being funded to be able to spend more time with a participant than an LAC could expect, the effectiveness of decision support by a Support Coordinator is reduced by their superficial knowledge of the participant especially given the increased complexity of participants, the lack of face to face engagement necessary to develop trust and provide opportunities to enhance decision making capacity and the possible conflict of interest arising from being employed by the provider of other supports in the participant plan.

The IAC has expressed concern that at least in its current operation, the Support Coordinator role does not require the skill nor the depth of relationship to enable trust and insight critical for effective support for decision making. The IAC has stressed at minimum that the Support Coordinator should be independent from a SIL provider for participants in shared supported accommodation. Other stakeholders who contributed to the development of this paper expressed a preference that any decision supporter be independent of all providers of core supports used by the participant.

¹⁹ WaIS, *Supported decision making*, WA Individualised Services Accessed at <http://waindividualisedservices.org.au/supported-decision-making-project-resources/>, 18 February 2018

²⁰ where for example a parent, who is desperate for a break 'supports' a participant to 'chose' a respite house over some other service types

²¹ Mental health Australia and ADACAS (2016) op cit, p18

²² Mental health Australia and ADACAS (2016) op cit p24

Steps in supporting decision making

Steps in supporting decision making are decision and time specific and work that increases the capacity of both the decision maker and the decision supporter increase the probability that decisions in fact reflect the will and preference of the decision-maker.

Many participants with intellectual disability have had little experience in making decisions and hence capacity building starts by providing opportunities for the person to make small day-to-day decisions such as what to wear and what to eat for breakfast so that over time and with support, the person is able to make decisions of greater consequence.

The fluctuations in functioning with cycles of illness and wellness, impacts on the decision making capacity of participants with psychosocial disability. In many states and territories, participants with psychosocial disability can call upon the legal mechanisms of nominated persons and advanced statements to give voice to their will and preferences, at least in clinical settings) but their life experiences of breakdown in family relationships and challenges in maintaining friendships can leave them with few if any decision supporters to call upon.

The NDIS is seen as requiring a 'labour of choice' for participants with psychosocial disability where the multitude and complexity of choices and decisions require significant cognitive, relational and emotional work.²³ The timing and sequencing of decisions are critical to maximise the participation of a decision maker with cognitive impairment.

A supporter can assist a decision-maker by breaking decisions down into smaller more easily identifiable components, identifying options and where possible creating opportunities for the person to experience the option and to understand the consequences and practicalities of each option. For example, in helping a person make decisions about a holiday, a decision making supporter might help the person think about:

- if anyone else needs to be involved in or is affected by the decision (family or friend with whom the person hopes to share the holiday, persons who may provide support on the holiday);
- any influences or restrictions on the decision (e.g. budget, sharing accommodation, accessibility of accommodation);
- time frames for decision (e.g. to get best price); and
- consequences of decisions (e.g. a local holiday will cost less, a long holiday may mean missing routine commitments e.g. TAFE classes etc.).

Most well-intentioned informal supporters are used to making decisions on behalf of people with disability. Decision making frameworks and discussion can assist the

²³ Wilson, E. & Pollock, S., (2018) Understanding people with psychosocial disability as choice-makers in the context of the NDIS (published paper) Pviii

supporter to develop self-awareness and reflection regarding the potential conflict between their own preferences and the preferences of the person whose decision making they are supporting.

Resources that break support for decision making into identifiable steps assists us to assess the capacity of decision making supporters to be effective. Bigby and Douglas²⁴ guide decision supporters to:

- know the person;
- identify and describe decisions;
- understand the person's will and preferences for the decision;
- refine the decision taking into account constraints;
- decide whether the particular decision is self-generated²⁵, shared²⁶ or substitute²⁷;
- make the decision; and
- implement the decision.

People with Disability Australia draws on the Article 12 of the UNCRPD to argue that no decision, especially decisions in the context of the NDIS, should be substitute decisions and that with sufficient support, each participant can make all NDIS related decisions.

Whilst in practice, decision making is messier than 7 steps in a sequence, the elements identified in the framework assist in guiding decision making supporters.

Emerging knowledge

In Australia, between 2010 and 2017, a series of projects in NSW, Queensland, Victoria, ACT, WA and South Australia piloted various models of delivering decision making support including different approaches to:

- developing decision making capacity
- identifying, developing and supporting decision making supporters including
 - supporting families, friends and frontline support staff
 - recruiting volunteers
 - using paid/professional supporters
- formal agreements (e.g. Canada: representation agreements and microboards)
- people under financial management with implications for capacity building and plan management.

²⁴ Bigby, C., Douglas, J., (2015) Support for decision making: a practice framework. Living with Disability Research Centre, La Trobe University

²⁵ Supporters provide information and experience that enables the person to act on their own behalf based on their will & preferences & rights taking account of resource constraints and consequences.

²⁶ Supporters provide information and experience that enables the person to express their will and preferences and if necessary interpret these, and assist in taking account of resource constraints and consequences

²⁷ Supporters provide information and experience and enable the person to express their will and preference and if necessary interpret these taking account of resource constraints and consequences. Supporters moderate the person's will, preferences and rights if there are likely to be harmful consequences and the person does not have the ability to appreciate these.

The pilots were small scale, conducted by both statutory and non-statutory bodies, and adopted similar designs centred on supporting a decision maker/supporter dyad with. Primarily, participants were people with mild intellectual disability.

The pilots demonstrated positive outcomes: that with support, a person's capacity and confidence to make decisions increased. Pilot participants gained experience in making decisions in a wide range of activities and experienced greater autonomy. The pilots also demonstrated positive outcomes for supporters who generally derived satisfaction from the benefits they perceived for the person they supported.

Themes that emerged from the pilots included the difficulty in securing supporters and their limited experience and initial low expectations of the capacity of the person they were supporting and the value of pilot program staff in supporting both decision makers and supporters. Written resources were perceived to be of variable value.

Importantly, the pilots demonstrate the feasibility of providing support for decision making but the descriptive nature of the evaluations means they do not resolve issues involved in delivering support.

Knowledge in the area continues to grow. The Australian Supported Decision making Network is a hub of expertise and a lead in communities of practice. Training materials are currently being implemented through a national partnership between National Disability Services and support providers²⁸; materials developed by the NSW Office of the Public Guardian and evaluated by the Social Policy Research Centre²⁹ are being tested for their capacity to address issues of workers who act as gatekeepers to capacity building; a pilot is exploring support for people to engage in consumer transactions in the finance, telecommunications, insurance and utilities industries³⁰ and other research has explored the choice making decisions for people with psychosocial disability in the NDIS.

Support for Decision making Framework

The framework has been developed to guide good practice in support for decision making. Support for decision making starts with the assumption of capacity and a simple assessment to evaluate the need for decision support based on the unique circumstances of the person with disability, including the presence and quality of informal decision support.

The framework identifies:

- core strategies to strengthen decision support (described as core decision-supports) (Table 1)

²⁸ <https://www.nds.org.au/events-and-training/all-events-and-training/supported-decision-making-e-learning-module-3039>

²⁹ <https://www.sprc.unsw.edu.au/research/projects/supported-decision-making-project-phase-2/>

³⁰ Maker, Y., Supporting people with decision making impairments to be full economic actors Accessed at <https://socialequity.unimelb.edu.au/news/latest/supporting-people-with-decision-making-impairments-to-be-full-economic-actors> 19 February, 2019

- the need for and nature of decision support:
 - for participants with intellectual disability and cognitive impairment across the lifespan (Table 2)
 - for participants with psychosocial disability (Table 3)
 - across the NDIS (Table 4).

Strategies to strengthen decision support

The strategies outlined in Table 1 assess and strengthen the capacity of the decision maker and the capacity of decision supporters. They mitigate against the risk that participants are not supported to make decisions or that decision support is weak and hence are described as core mitigation strategies.

Table 1 Strategies to strengthen decision support (core decision supports)

Strategies:	Examples
That identify the need for decision support	Frameworks that identify the presence and quality of decision support May use participant response to choice and control questions in outcomes questions in planning meeting to contribute to identification of need
That strengthen decision making	Individual capacity building in choice and decision making Participation in peer networks
That strengthen decision support	Decision support skill building workshops and communities of practice Opportunity for discussion about individual situations
That increase the number and quality of people that may provide decision support	Circles of support Mentoring programs Peer workers
That connect the person to others who understand their circumstance	Peer networks
That ensure the availability of decision support	Approach that allocates support for decision making to complement decision supports already in place.

For an isolated participant who has no informal support and is in need of decision support, good practice would suggest that he/she will:

- be identified early
- be supported to build their decision making supports including:

- receiving capacity building to build choice and decision making skills
- the development of mechanisms that support decision making such as a circle of support, being linked to a mentoring program or peer worker
- be allocated resources to support decision making including to assist the supporter to strengthen their practice of supporting decisions
- be encouraged to join a peer network.

Support for decision making for participants with intellectual disability and cognitive impairment across the lifespan

Table 2 uses the notion of ‘important to’ and ‘important for’ to point to the complexity required in many decisions. The choices and decisions of little children demonstrate what is ‘important to’ them. Their parents usually temper their children’s choices with what is ‘important for’ them. Over time, children, young people and adults take increasing responsibility for balancing ‘important to’ and ‘important for’ and even the most competent adults often make decisions with little regard to what is important for them. People with disability have the same ‘right’ to make decisions that do not reflect what is ‘important for’ them. One of the dilemmas of decision making supporters is to enable the dignity of risk by scaffolding the consequences of poor decisions and knowing how best to enable the person to learn from their poor decisions.

Table 2 compares processes used to support decision making for people with and without disability and for people with psychosocial disability, times with less capacity and times with capacity comparing the traditional ‘best interests’ approach with good decision support practice expected in the NDIS.

The key message is that the most effective support for decision making across the lifespan provides increasing opportunities for the person to make day-to-day decisions, explicitly 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 of decisions with the person and others as appropriate, and allows the person to experience the safe consequences of decisions.

Table 2 Support for decision making for participants with intellectual disability and cognitive impairment across the lifespan

Age	Nature of choices and decisions	S for DM for peers <u>without</u> disability: by whom, how	Good practice in S for DM for people with cognitive disability	Traditional 'best interests' approach	In the NDIS	Mitigation for poor S for DM
0-5	<p>All choices reflect 'important to' (I want) with increasing consciousness of 'important for' (Mummy makes me)</p> <p>May choose food, toys, clothes and playmates from within available options</p> <p>NDIS decisions made by parents</p>	<p>Provided by parents, health professionals, significant care givers and teachers</p> <p><u>How</u></p> <p>Offering new experiences and choices</p> <p>Allowing child to experience safe consequences of decisions</p>	<p>The same source and nature of support as children without disability but may be introduced at a slower pace</p>	<p>Parents make decisions</p>	<p>Parents make decisions</p>	<p>Core decision support strategies</p>

Age	Nature of choices and decisions	S for DM for peers <u>without</u> disability: by whom, how	Good practice in S for DM for people with cognitive disability	Traditional 'best interests' approach	In the NDIS	Mitigation for poor S for DM
6-14	<p>Most choices reflect 'important to' with increasing consciousness of 'important for'.</p> <p>Children have significant voice and make decisions related to friends, interests, clothes, hair styles, school subjects, leisure activities, how to spend pocket money</p> <p>NDIS decisions made by parents</p>	<p>Provided by family, friends, health professionals, teachers, shop keepers, leaders of community activities, social media</p> <p>Peer pressure growing</p> <p><u>How</u></p> <p>Increasing choice</p> <p>Increasing opportunity to experience the safe consequences of decisions (note what is 'safe' will vary between individuals)</p>	<p>Most support from parents and teachers</p> <p><u>How</u></p> <p>Increasing opportunity to make day-to-day decisions</p> <p>Provision of explicit information in a manner 'right' for the individual</p> <p>Breaking decisions into smaller more easily identifiable components</p> <p>Opportunity to try different things</p> <p>Opportunity to talk through options, decisions and implications of decisions with child and others as appropriate</p> <p>Allowing child to experience safe consequences of decisions</p>	<p>Parents make decisions</p> <p>Child may have opportunity to make small day-to-day decisions</p>	<p>Parents make decisions but NDIS wants to see evidence that the decisions reflect what is important to the child as well as what is important for the child.</p>	<p>Core decision support strategies</p>

Age	Nature of choices and decisions	S for DM for peers <u>without</u> disability: by whom, how	Good practice in S for DM for people with cognitive disability	Traditional 'best interests' approach	In the NDIS	Mitigation for poor S for DM
15-18	<p>Choices reflect 'important to' with ever increasing responsibility for 'important for'</p> <p>Decisions of earlier years plus ways to experience increased independence, part time work, future career</p> <p>Increasingly involved in NDIS decisions related to access, pre-planning, plan implementation and review</p> <p>Increasingly involved in service selection, support planning and review</p>	<p>Provided by family, friends, teachers, health professionals, career counsellors, internet including social media.</p> <p>Peer group a strong influence and support</p> <p><u>How</u></p> <p>Allowing young person to experience consequences of decisions</p>	<p>Family remains significant support for decision making supplemented by teachers and other leadership figures and perhaps support workers</p> <p><u>How</u></p> <p>Strategies similar to those of young years in order to increase opportunity to make decisions and calibrate support according to increasing capacity of young person</p>	<p>Increasing options to make decisions over day-to-day matters.</p> <p>With fewer opportunities to make decisions, the person often has less practice and less competence.</p>	<p>Young person expresses views, parents might assist to understand constraints on decisions</p> <p>Parents and increasingly young persons make decisions demonstrating evidence of what is important to as well as what is important for the young person.</p>	<p>Core decision support strategies</p> <p>Capacity building in choice and control</p>

Age	Nature of choices and decisions	S for DM for peers <u>without</u> disability: by whom, how	Good practice in S for DM for people with cognitive disability	Traditional 'best interests' approach	In the NDIS	Mitigation for poor S for DM
18-+	<p>Adults must balance 'important to' with 'important for'.</p> <p>Responsible for decisions and consequences although often ongoing assistance of family</p> <p>Decisions made in relation to career, work, home, friendships, interest</p> <p>Increasingly involved in NDIS decisions related to access, pre-planning, plan implementation and review</p> <p>Increasingly involved in service selection, support planning and review</p>	<p>Provided by peers, families, health professionals, career counsellors, employers, banks and finance companies, Internet including social media</p> <p><u>How</u></p> <p>Person makes decisions and experiences consequences of decisions</p>	<p>Support from families, peers, support workers</p> <p><u>How</u></p> <p>Similar strategies to increase opportunity to make decisions and calibrate support according to increasing capacity of person</p>	<p>Parents make important decisions</p> <p>As with 15-18year olds</p>	<p>Participant is expected to make decisions</p> <p>Support for decision making available or provided</p>	<p>Core decision support strategies</p> <p>Capacity building in choice and control</p>

Support for decision making for participants with psychosocial disability

Table 3 examines support for decision making for people with psychosocial disability where fluctuating function impacts on decision making capacity and decision making support needs to be calibrated to respond to mental health status as well as all other individual and environmental characteristics.

The table presents a binary picture of wellness and illness, meant merely to reflect end points on the continuum of mental health status. Work by Pollock³¹ has identified 5 groupings of people with psychosocial disability including people:

- in crisis,
- struggling in the community,
- stable in the community,
- potential to thrive and
- thriving.

³¹ Pollock, S., Mind Australia

Table 3 Support for decision making for people with psychosocial disability

Mental health status	Nature of choices and decisions	S for DM for peers <u>without</u> disability: by whom, how	Good practice in S for DM for people with psychosocial disability	Traditional 'best interests' approach	In the NDIS	Mitigation for poor S for DM
Thriving/ potential to thrive	<p>Lifestyle decisions</p> <p>Adults must balance 'important to' with 'important for'.</p> <p>Responsible for decisions and consequences</p> <p>Decisions made in relation to career, work, home, friendships, interest, and health.</p> <p>NDIS decisions about access, pre-planning, planning, plan implementation and review, appeals.</p>	<p>Provided by peers, families, health professionals, career counsellors, employers, banks and finance companies, Internet including social media</p> <p><u>How</u></p> <p>Person experiences consequences of decisions</p>	<p>Recognition of impact of poverty, isolation, violence, abuse & trauma</p> <p>Encouragement to make advanced statements and identify nominated persons</p> <p>Support from peers, support workers, family (for some)</p> <p>Paid independent decision supporters preferred by many</p> <p><u>How</u></p> <p>Make decisions with calibrated support according to capacity of person</p> <p>Peers working effectively providing information and helping person to critique options</p>	Participant makes own decisions	Participant makes own decisions	<p>Core decision support strategies</p> <p>Capacity building in choice and control</p>

Mental health status	Nature of choices and decisions	S for DM for peers <u>without</u> disability: by whom, how	Good practice in S for DM for people with psychosocial disability	Traditional 'best interests' approach	In the NDIS	Mitigation for poor S for DM
In crisis or struggling in the community	Lifestyle decisions Access, pre-planning, planning, plan implementation and review, appeals	Provided by peers, families health professionals, career counsellors, employers, banks and finance companies, Internet including social media <u>How</u> Person makes decisions and experiences consequences of decisions	Support from nominated person, peers, support workers, family (for some) Paid independent decision supporters preferred by many <u>How</u> Guidance via advanced statements and nominated persons Strategies to increase opportunity to make decisions and calibrate support according to capacity of person Peers working effectively providing information and helping person to critique options.	Decisions made by others in person's best interest	Participant is expected to make decisions Support for decision making available or provided	Core decision support strategies Capacity building in choice and control

Support for decision making in the NDIS

Table 4 outlines possibilities for supporting participant decision making in the NDIS including families and friends, nominees, LACs, planners, Support Coordinators, peer networks, support providers and independent decision supporters. For each option, the table canvases what good practice might look like, opportunities, limitations and strategies to mitigate the limitations.

Good support for decision making must recognise the increased vulnerability of the person including the impact of poverty, isolation, violence, abuse, trauma and health (including mental health) on the participant's life and decision making.

The key message is that the NDIS requires strategies to: identify the need for decision support; increase the number and quality of people who may provide decision-support; strengthen the quality of decision support; and connect the person to others who understand their circumstances. A planned strategy to address these issues including practice guidance with specific requirements for all paid decision supporters, will give effect to key strategies to mitigate the risks associated with different options.

Table 4 Support for decision making in the NDIS

Decision supporter	Current practice in S for D M	Good practice in S for D M	Opportunities	Limitations	Strategies to mitigate limitations
Family / friends	Often make decision on behalf of the person	Reflective Understand and use steps in support for decision- making	Knows the person well Positive commitment and intentions Probably able to refine decisions taking into account constraints but may only consider a restricted range of options	May be estranged from the person May be reluctant to admit the person's decision making ability May have a conflict of interest May not be aware of extent of substitute decision making May not be aware of low expectations Don't know what they don't know and may need to be exposed to new options	Information about contemporary options readily available through trusted sources DPFOs provide workshops in S for DM Core decision support strategies
Nominees	Make decisions on behalf of the person	Are only appointed where it is not possible to support person to make decisions Consult the person	Knows the person well Positive commitment and intentions Probably able to refine decisions taking into account constraints but may only consider a	Make substitute decisions Have low expectations Don't know and may need to be exposed to new options NDIA does not monitor nominees in action	NDIA guidance and support for the role of nominees Information about contemporary options readily available through trusted sources

Decision supporter	Current practice in S for D M	Good practice in S for D M	Opportunities	Limitations	Strategies to mitigate limitations
		Build the capacity of the person to make decisions Avoid or manage conflict of interest	restricted range of options NDIA requirements on nominees		DPOFOs provide workshops in S for DM Core decision support strategies
LAC/ ECEI partners	Supports person to develop NDIS plan Can identify and describe NDIS decisions In limited circumstances, assists person to implement decisions	No current practice guidance	Knows NDIS and local community well May talk about new options but while relationship is superficial, impact will be low	Superficial knowledge of person Only focuses on high level decisions Unlikely to be able to refine decision by taking account of constraints Don't know what they don't know May not be experienced in supporting decision making in a capacity building way Other role responsibilities may diminish time available to support decision making	Involvement of family and friends Pre-planning support Direct practice guidance Core decision support strategies
Planners	Supports person to develop NDIS plan	No current practice guidance	Knows the NDIS well	Superficial knowledge of person	

Decision supporter	Current practice in S for D M	Good practice in S for D M	Opportunities	Limitations	Strategies to mitigate limitations
	Can identify and describe NDIS decisions		Links participant with Support Coordinator to implement the plan	<p>Only focuses on NIS and high level decisions</p> <p>Significant conflict of interest arises from their responsibility to determine funding level</p> <p>Unlikely to be able to refine decision by taking account of constraints</p> <p>Don't know what they don't know</p> <p>May not be experienced in supporting decision making in a capacity building way</p> <p>Other role responsibilities may diminish time available to support decision making</p>	
Support Coordinator (SC)	Often chosen by SIL provider Level of participant involvement in decision making	Has knowledge and skills in working with people with participant's profile and life circumstances	Knows NDIS Should know local community Relationship funded over time but limitations	If employed by provider of core supports will have conflict of interest May not be experienced in supporting decision	SC independent of funded supports Direct practice guidance Core decision support strategies

Decision supporter	Current practice in S for D M	Good practice in S for D M	Opportunities	Limitations	Strategies to mitigate limitations
	<p>variable: SC often makes and implements decisions on behalf of participant</p> <p>Little active capacity building</p>	<p>Funded for significantly more hours enabling use of steps in support for decision making</p>	<p>of role may inhibit active capacity building</p> <p>Should be aware of and talk about new options</p>	<p>making in a capacity building way</p> <p>Don't know what they don't know</p> <p>Only focuses on high level decisions</p> <p>Unlikely to have regular face to face contact with participant</p> <p>Other role responsibilities may diminish time available to support decision making</p>	
Peer networks	<p>Supports person to have confidence in decision making</p> <p>Provides a sounding board for people to share challenges and dilemmas</p>	<p>Run workshops that increase self-advocacy and decision making skills</p> <p>Peer network hosted by organisation with capacity to provide/ ensure the provision of additional support for member struggling with important life decision</p>	<p>Know about NDIS</p> <p>Know about local community and opportunities</p> <p>Relationships over time</p> <p>Should be aware of and talk about new options</p>	<p>Most vulnerable participants unlikely to be members of peer networks</p> <p>Don't know what they don't know</p>	<p>Peer networks hosted by Disabled Persons and Family Organisations (DPFOs)</p> <p>Core decision support strategies</p>

Decision supporter	Current practice in S for D M	Good practice in S for D M	Opportunities	Limitations	Strategies to mitigate limitations
Support Provider	Variable quality Unsophisticated	Paid support facilitates opportunities for participants to make day-to-day decisions	Knows the participant well Is conflicted in talking about options outside their service	Don't know what they don't know Conflict of interest in relation to major life decisions May not be experienced in supporting decision making in a capacity building way Other role responsibilities may diminish time available to support decision making	Direct practice guidance Participation in peer networks Core decision support strategies
Independent decision making supporter	Not available but often first preference of participants with psychosocial disability	Understands and uses steps in support for decision making Backed up by program that understands quality support for decision making Has knowledge and skills in working with people with participant's profile and life circumstances	No conflict of interest Knows about local community and opportunities Should be aware of and talk about new options	Need to get to know the participant Don't know what they don't know	Availability of ILC program to support decision making supporters Direct practice guidance Core decision support strategies

Risks

Participants are not supported to make decisions

The impact of the NDIS not supporting participants to make decisions is significant. Without this support, the platform of choice and control that differentiates the NDIS from previous systems will be diminished leading to a massively lost opportunity for Australians with disability. There is also risk of reputational damage for the NDIA due to inconsistency between the stated principles of the scheme and lack of investment to support participant and family capability.

The NDIS is the most significant opportunity to uphold and enshrine the basic human rights of the most marginalised and disadvantaged people with disability. Exercising choice and control in their own lives and over their own support arrangements is one such right that has now been legislated nationally.

Participants “don’t know what they don’t know”. Without support in the form of accessible information and the opportunity to see, hear about and try alternate options, participants will remain in traditional services that tend to cost more.

Identified risks and mitigation strategies are identified below.

Participants in need of decision support are not identified early

Mitigation strategies

Assessment of the need for decision support: The NDIA to develop a framework that in a simple informal way, assesses the quality of current informal support for decision making. This would be used by LACs and planners and would mitigate the risk that participants in need of decision support are not identified. The practice guidance would include pathways to decision making support.

Practice guidance: Practice guidance that specifically addresses the issue of support for decision making and identifies strategies to address limitations arising from current decision supports would mitigate the risk of the NDIS continuing to legitimise substitute decision making.

For example, a participant with actively engaged family who seem to be informally making decisions on behalf of their adult son could be directed to ILC services that provide seminars on decision making for supporters.

For example, 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, 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 quality of decision support remains poor

Mitigation strategies

Capacity building for supporters: Strategies that build the capacity of decision supporters will assist the vast majority of well-meaning families and friends to move from making decisions for the person based on their best interest to supporting the person to make decisions that reflect their will and preferences in safeguarded ways.

The NDIA could commission support for decision making services in the ILC for participants and informal supporters to learn about and enhance skills in decision making.

The NDIA could provide training and development for NDIA staff and LAC partners to strengthen their role in supporting participants to make decisions.

Reasonable and necessary support for decision making: 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.

Requirements on Support Coordinators: The NDIA could strengthen requirements on Support Coordinators in relation to support for decision making.

Requirements on providers: The NDIA could 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 is support for each participant*.³².

The way forward

To meet its obligations and aspiration to provide real choice, the IAC recommends that:

1. The Board endorse the proposed framework for support for decision making provided. This framework:
 - 1.1. Identifies strategies to strengthen decision support
 - 1.2. describes good practice in support for decision making for participants with intellectual disability and cognitive impairment across the life span, for participants with psychosocial disability and in the NDIS
 - 1.3. identifies eight (8) options to support decision making in the NDIS

³² NDIS Quality and Safeguards Commission (2018), NDIS Practice Standards, Rights and responsibilities p6

- 1.4. identifies current practice, good practice, limitations and strategies to mitigate the limitations for each option
- 1.5. will guide the NDIA in the development of a consistent support for decision making approach that meets the Scheme's obligations and aspirations to provide real choice for people with disability.
2. The Board directs the NDIA to operationalise the framework, including by:
 - 2.1. developing and rolling out NDIA capability to operationalise the framework including strategies to mitigate risks
 - 2.2. commissioning services in the ILC to build awareness and capability for community supporters, family, friends and carers to support people with disability to make decisions
 - 2.3. developing requirements for Support Coordinators in working with participants to support their decision making
 - 2.4. adjusting the intent, description and price of the item *Assistance with decision making, daily planning and budgeting* to a price reflective of the skill base and time components required.
3. The Board directs the Agency to implement and monitor the framework, including continuing to innovate and measuring long-term impact.

References

Australian Law Reform Commission, (2014) *Equality, capacity and disability in Commonwealth laws*, viewed 25 January 2016

<https://www.alrc.gov.au/publications/national-decision-making-principles>

Australian Supported Decision Making Network, (2016) *Discussion Paper calling for the development of a National Supported Decision Making Framework*, Available through Justine_O'Neill@opg.nsw.gov.au

Bigby, C., & Douglas, J. (2015). Support for decision making - A practice framework. Living with Disability Research Centre, La Trobe University

Bigby, C., Douglas, J., & Hamilton, L. (2015). Support for decision making: A guide for trainers. Living with Disability Research Centre, La Trobe University

Bigby, C., Whiteside, M. & Douglas, J. (2015), *Supporting people with cognitive disabilities in decision making – processes and dilemmas*, Living with Disability Research Centre, La Trobe University

Brophy, L., McSherry, B., Kokanovic, R., Moeller-Saxone, K., Herrman, H., Guidelines for supported decision making in mental health services Accessed at <http://healthtalkaustralia.org/wp-content/uploads/2017/09/Guidelines-for-Supported-Decision-making-in-Mental-Health-Services.pdf> 16 February 2019

Burgen and Chesterman, J., 2015 viewed 19 January 2016

<http://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making>

Department of Health (2010), *Principle of recovery oriented mental health practice*, Australian Government Mental Health website. Accessed <http://www.health.gov.au/internet/publications/publishing.nsf/Content%20/mental-pubs-i-nongov-toc~mental-pubs-i-nongov-pri> 18 February 2019

Family and Community Services (2015), *My life, my decision, An independent evaluation of the supported decision making pilot* viewed 19 January 2016

https://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/supporte-d-decision-making/sdm-background-learnings

Kokanovic, R., Brophy, L., McSherry, B., Hill, N., Johnston-Ataata, K., Moeller-Saxone, K., & Hermann, H., (2017) *Options for supported decision making to enhance recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melbourne

Mental Health Australia, ADACAS (2016) *Supported decision making, psychosocial disability and the NDIS*, Accessed

https://mhaustralia.org/sites/default/files/docs/supported_decision_making_psychosocial_disability_and_the_ndis.pdf 16 February 2019

Pollock, S., Stratford, A., Brophy, L., Wilson, E., & Campain, R., (2018) *The challenge of choice for people with psychosocial disability in the NDIS*, Available from Mind Australia

Ramcharan, P., Leighton, D., Moors, R., Laragy, C., Despott, N., Guven, N., (2013) (2013) *It's My choice Tool Kit*, viewed 25 January 2016

http://www.inclusion.melbourne/wp-content/uploads/2013/06/Its_My_Choice_Vol2_web.pdf

Resources for supported decision making Accessed at http://healthtalkaustralia.org/wp-content/uploads/2017/09/Fact-Sheet-4-Resources-for-Supported-Decision_making.pdf 19 February 2019

United Nations Committee on the Rights of Persons with Disabilities (2014). *General Comment No.1. Article 12: Equal recognition before the law*. Adopted 11 April ,2014. Accessed at <x-webdoc://4158B759-E8D4-49D3-8B6B-92FDA5846194/www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx> on 27 January 2016.

Victorian Government Supporting Decision Making Guide (which includes resources for [people with disability](#) and a [guide for disability support workers](#)): <http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/supporting-decision-making-guide>

WA Individualised Services – <http://waindividualisedservices.org.au/supported-decision-making-project-resources/>

Wilson, E. & Pollock, S., (2018) Understanding people with psychosocial disability as choice-makers in the context of the NDIS (published paper)

Wilson, E., Campain, R., Pollock, S., Brophy, L. & Stratford, A. (2018) *Understanding people with psychosocial disability as choice-makers in the context of the NDIS*, Burwood, Deakin p viii