Good Practice in Supported Decision-making for People with Disability

Final Report

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Acknowledgements

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Abbreviations

ABS	Australian Bureau of Statistics
ALRC	Australian Law Reform Commission
Committee	The United Nations Committee of the Rights of Persons with Disabilities
CRPD	The United Nations *Convention on the Rights of Persons with Disabilities*
DSS	Australian Government, Department of Social Services
Nd.	Non-dated
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
SDM	Supported decision-making
SPRC	Social Policy Research Centre, University of New South Wales
UNSW	University of New South Wales

Key terms used in this report

Cognitive impairment	Cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life and may require support to make decisions. People with cognitive impairment include people with intellectual disability or foetal alcohol spectrum disorder (FASD) they were born with, an acquired brain injury, or psychosocial disability where cognition can be impaired through episodes of mental distress or emotional trauma and medication. Cognitive impairment is not static, it can be episodic, improve or develop, and it can also degenerate. The ability to make decisions can exist along a spectrum and can be context sensitive. The ability to make a decision is always the starting assumption.
Psychosocial disability	Psychosocial disability arises when someone who experiences mental or emotional distress interacts with a social environment that presents barriers to their equality with others. People with psychosocial disability may identify with a variety of terms including mental health consumer, a person with lived experience of a mental health condition, or neuro-diverse. People may refer to their experiences as mental distress or crisis, trauma, neurodiversity or mental health challenges.
Rights, will and preferences	'Rights' are all human rights and fundamental freedoms. 'Will' means larger life goals, political perspectives, emotional and spiritual development and views, gender and sexuality identity for example. 'Preferences' means choices regarding day-to-day- activities, aesthetic preferences, and similar. 'Will' and 'preferences' is also regularly connected with 'rights' in the sense that supported decision-making is about giving effect to the will, preferences and *rights* of a person requiring decision-making support. 'In cases where it is not possible to determine the will and preferences of the person, the default position must be to consider the human rights relevant to the situation as the guide for the decision to be made' (ALRC 2014, para 3.53).

Supported decision-making	Supported decision-making can be better understood as the process of decision-making support by which a supporter acknowledges that a person with cognitive impairment at all times retains full legal personhood, and inalienable Human Rights, and seeks to identify the 'will and preferences' of a person requiring decision-making support and communicate those to others when required, so that the person requiring support is at all times empowered to exercise their legal capacity, and direct choice and control over their life goals. Supported decision-making is to be contrasted with substitute decision-making, where decisions are made for the person by a third-party. This includes schemes where a Court or Tribunal, if satisfied that a person is not able to make decisions that are in that person's best interests, will appoint a person to make decisions for the person with cognitive impairment after considering what their 'best interests' are, effectively denying the person with cognitive impairment their legal personhood, autonomy, and legal capacity. Substitute decision-making may be assumed by a family member, carer or service provider undermining the rights of the individual to make their own decision – supported or otherwise.
Supporter	A supporter is a person who: • assists a person with cognitive impairment to identify and express their will and preferences • upholds and gives effect to the persons rights • who assists them to understand the process of decision-making; assists them in identifying choices, and • ensures that decisions subsequently made by the person requiring decision-making support are acknowledged as decisions of that person for all legal purposes. Supporters can be in 'informal' arrangements (such as a family member or trusted friend) or a more 'formal' arrangement where a supporter (including a family/trusted person) is appointed by an agency as a service, and there is a written agreement between the parties as to scope and obligations; for example, in respect of decision-making support.

Summary

The Australian Government Department of Social Services (DSS) contracted researchers at the University of New South Wales to develop guidelines for supported decision-making. Everyone has the right to make decisions – many people look to others for support to help make decisions. This may include assistance in understanding the choices available, understanding the impact of those choices, and helping implement those choices.

People with cognitive impairment may need additional support for day-to-day decision-making as well as more significant decisions. This support may be provided formally through services, and informally by family and friends. This is different to substitute decision-making where someone else makes a decision for them – this may be done by parents (for someone under 18 years) or by legally appointed guardians or trustees.

The research:

- Reviewed existing research on supported decision-making. This identified key components, legal requirements, and safeguards of supported decision-making.

- Engaged key stakeholders in terms of current decision-making supports and support needs. This included government stakeholders, statutory organisations and disability organisations.

- Led to the development of a Principles and Guide for supported decision-making and identified how stakeholders can implement the Principles and Guide.

Principles and Guide

The Principles and Guide were developed to be compliant with Australia's international law obligations under the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD). The Principles and Guide were also based on National Principles developed in an earlier project completed by the Australian Law Reform Commission (2014).

The Principles and Guide developed for this project:

- Identify key elements of supported decision making. This provides a common understanding of what supported decision-making is – and is not.

- Identify how and what stakeholders can do to support decision-making. This includes identifying the outcomes these steps are expected to achieve.

The Principles and Guide is designed to meet the needs of different people with diverse requirements. Key steps and outcomes are identified for government and society; organisations, services and professionals; informal supports; and the person making decisions.

Each organisation may need to tailor the Principles and Guide and consider what tools, resources and supports may be needed to implement the Principles and Guide based on the organisation's functions.

1 Introduction

The Australian Government Department of Social Services (DSS) contracted a research team from the Social Policy Research Centre (SPRC) at UNSW Australia to identify and develop evidence-based good practice guidelines for supported decision-making, compliant with the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD), which have practical application and work across systems such as justice, mental health, health, and child protection.

The right to make decisions is enshrined in the CRPD. Article 3 (General Principles) include inherent dignity, as well as individual autonomy (including the freedom to make one's own choices), and article 12 (Equal recognition before the law) accords persons with disabilities with legal capacity on an equal basis as others in all aspects of life. Having ratified the CRPD, the Australian Government commits to develop 'appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity' (UNCRPD 2006).

Many existing disability service models in Australia pre-date the CRPD provisions. Consequently, a considerable proportion of pre-existing services now accessed by NDIS participants have operations, structures and cultures predicated on decisions made by others based on the best interests of the person. As such, there is a need for formal guidance material to assist people with disability, their guardians or legal decision-maker, families, support workers and other key parties to promote best-practice supported decision-making procedures and practices, especially across key interfaces[1] between the NDIS and the justice, health, mental health, and child protection systems.

The provisions of the CRPD require a significant shift from current policy and practice in Australia. This transition will require significant capacity building for individuals, services and systems in order for people with disability to exercise their legal capacity. This report highlights the barriers and facilitators to the operationalisation of article 12 of the CRPD, Equal recognition before the law. This report also proposes Principles and a Guide to enable organisations to operationalise supported decision-making.

This final report:

* describes the research method used (Section 2)

* presents a summary of the desk top review (Section 3)

* presents the key findings from the consultation process (Section 4)

* proposes Principles and a Guide for supported decision-making (Section 5)

* identifies how organisations might operationalise supported decision-making and makes recommendations about how systems could better interact in the future to enhance supported decision-making in practice (Section 6).

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[1] https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf

2 Approach and methodology

This section presents the approach and methodology used for the study. The study was designed to accommodate the short timeframe and was mindful of other DSS and NDIA studies running concurrently.

The approach included:

- a desk top review of national and international policy frameworks, academic and grey literature, to inform the development of a draft supported decision-making operational guide
- consultation with key stakeholders to refine the draft operational guide
- reporting on how systems could better interact in the future to enhance supported decision-making in practice.

The study received approval from UNSW Human Research Ethics Committee, reference HC210061.

2.1   Desk top review

This desktop review was informed by peer-reviewed articles, grey literature, project and program reports, legislative reviews, guides, policy papers and similar from Australian and international jurisdictions. It was further informed by feedback received from the Department of Social Services on previous iterations, and through feedback received through the separate stakeholder consultation process.

The general question guiding the desktop review is:

> **What evidence-based best practice principles can be ascertained from the literature in respect of the design and/or implementation of supported decision-making programs/frameworks/strategies and similar?**

A wide search strategy was applied using databases that had a broad coverage of academic literature such as: APAFT, APAIS-ATSIS, Scopus. Social Science database, AGIS, SSRN, ProQuest Social Science, Proquest 5000, Web of Science. Google Scholar and Google searches were also used extensively to identify a significant amount of grey literature on this subject. In addition, a manual search of the reference lists of selected records/studies was undertaken, and this proved useful to focus on key search terms, specific journals and specific authors. The focus as much as possible was on material from 2014 onwards.

Key search terms included combinations of the following: "supported decision-making", "CRPD article 12", "guardianship", "reform", "evaluation", "cognitive disability", "justice", "mental health", "'best interests", "will preferences rights".

There was a large amount of material identified of varying quality and relevance. The initial review process resulted in about 200 items for further review. This further review resulted in the select reference list contained at the end of the desktop review. This reference list is organised around the following themes to assist useability:

- Guides, frameworks, and United Nations material
- Reports and evaluations
- Journal articles and book chapters
- Presentations, conference papers and online resources

The desk top review is provided as a separate report and informed the development of a draft supported decision-making operational guide which formed the basis for consultation.

2.2   Consultation document

The desk-top review culminated in the development of a consultation document, which included information about the project, background information about supported decision-making (replicated in Appendix A), consultation questions, and a high-level program logic for comment (the start of the Principles and Guide). The program logic outlined the key principles of supported decision-making and how they may be implemented across systems (government) and society, services, and individuals who may require support. In particular, the program logic identified key elements to operationalise supported decision-making and provide a framework to assess whether supported decision-making initiatives are meeting their objectives.

2.3   Consultation process

A two-part consultation exercise was undertaken with key stakeholder groups. Stakeholders are defined as: government departments and disability representative and advocacy organisations, who have a working knowledge of or understanding of supported decision-making, or who have an organisational responsibility for engaging with supported decision-making. The consultation process and consultation material were developed in consultation with a human rights consultant.

Stakeholders were invited to take part in:

- a written consultation exercise – stakeholders were provided with written information and were asked to respond to a series of questions, and provide feedback on the draft operational guide on behalf of their organisation
- focus groups – stakeholders were invited to participate in a group discussion exploring the same questions provided in the written consultation exercise in more depth.

In total, 11 organisations provided a written response, while 40 individuals from 24 organisations participated in 6 focus groups held between 8 April and 15 April 2021.

Table 1 Summary of research participants

Stakeholder group	Number of organisations participating in the 6 focus groups	Number of participants in focus groups	Number of written responses from organisations
Government departments	2	14	3
Disability organisations	4	4	7
Statutory bodies	18	22	1
Total	24 organisations	40 participants	11 submissions

A discussion guide was used for both the written and verbal consultation with stakeholders. Participants were asked three key questions (prompts in italics):

1. **What are the key elements of good supported decision-making?**

   a. *Can you provide examples (good and bad) of your experience with supported decision-making?*

   b. *Can you identify the strengths and weaknesses of the current approach?*

   c. *What are the facilitators and barriers to supported decision-making?*

   d. *How you think good supported decision-making can be measured.*

2. **What types of capacity building are required for people with disability, supporters, professionals and organisations?**

   a. *Do you think there is a gap in current supported decision-making provisions in your jurisdiction?*

3. **How can supported decision-making processes be improved to implement the National Decision-Making Principles?**

Participants were also asked to consider responses in the context of specific areas or domains, for example real life examples relating to supported decision-making in mental health, health, child protection and justice.

2.4   Data analysis

Detailed notes and transcriptions of workshops, along with written submissions, were analysed to collate issues and answers related to each of the consultation questions. Data were coded using NVivo software and analysed to examine the overlap between the three research questions and how they related to systems (government) and society, services, informal supports (added as a result of the consultation) and individuals who may require support. The analysis is reported Section 4 and used to update the draft Principles and Guide (presented in Section 5).

2.5   Constraints on the study

The main constraints of the study were time and resourcing, which meant the scope of the project was narrow and a large consultation process was not possible. However, the study was conducted in line with the scope of the project and within the time and resources available.

- The scope of this study was set by DSS (the funder).

- Due to time constraints a desktop review was selected as being the most appropriate form of analysis for this project.

- 'Restrictive practices,' 'advanced care directives' and 'power of attorney' were not addressed directly in the desktop review. The ALRC (2014) has previously drawn attention to these in the context of article 12 of the CRPD. Several Australian and International jurisdictions either have or are undertaking legislative and policy reviews of such matters.

The consultation process was conducted with the following limitations:

- Many disability organisations have limited funding and staff available to contribute to such studies. They also have competing requirements of their time; for example, the ongoing Disability Royal Commission, NDIS reform, and the response to COVID-19. Some participants chose not to participate, others participated but highlighted their contributions would have been greater had they had more time to respond to the consultation.

2.6   Outputs from this study

There are several different outputs from this study which may be used to help inform the development of policy for people with disability across public service systems. To maximise utility of the outputs, they have been presented as complementary components that can be used together or separately depending on the audience and the level of required knowledge. This includes:

- The desk top review (available separately)

- A background to supported decision-making (Appendix A) that can be used to accompany the Principles and Guide (depending on audience)

- The components of the Principles and Guide (Appendices B–G)

- Additional resources (Appendix H).

Policy recommendations are presented in Section 6 to this report, including recommendations for future research.

3 Summary of desk top review

Supported decision-making originated in Canada in the 1990s as a process to challenge and overcome legal barriers hindering people with cognitive disabilities from receiving individualised funding. CRPD article 12 is the key mechanism by which supported decision-making is now realised. It seeks the discontinuation of substitute decision-making schemes based upon a third party's interpretation of the 'best interests' of a person with disability (as found in Australian Guardianship regimes), in favour of supported decision-making schemes where the 'will, preferences and rights' of a person with disability are to be given effect to at all times. It imposes a standard that there can be no limitation on legal capacity due to impairment, and requires states to ensure people with disability have the required support they need to exercise their legal capacity.

A human rights model of disability is the current interpretive framework by which compliance with the CRPD by states is measured. This model views people with disability as having equal worth, value and dignity as all human beings. It does not require a medical diagnosis. Critically, impairment of any kind is not a basis for any denial of human rights. CRPD article 12 places an obligation on states to provide the resources to support a person who may require decision-making support to have their 'will, preferences and rights' recognised.

In interpreting article 12 by the Committee of the CRPD declared there is no scope for retaining substitute decision-making, and to so results in non-compliance with the CRPD. Australia lodged an interpretive declaration in relation to article 12 denying it abolished substitute decision-making. The ALRC in 2014 report did also recommend retaining substitute decision-making, renamed it 'representative' decision-making and emphasised its use as a last resort for 'hard cases'. Relevantly, all Australian and International jurisdictions do, at the current time, provide a substitute decision-making option.

3.1 Supported decision-making

Supported decision-making has no fixed definition. It is not defined in the CRPD. A helpful way to think of SDM is as both a *practical process* and as *legal recognition* of that process. More specifically:

a. *Supported decision-making* as the legal and policy structures underpinning support for decision-making, including formal schemes that recognise the standing and role of supporters in providing support for decision-making, and

b. Support *for* decision-making as the practices undertaken by supporters when assisting a person in a decision-making process. This can also entail 'informal' support arrangements (such as in a family), and more formalised arrangements.

Essentially, in contrast to substitute decision-making, SDM involves the person *always retaining their legal capacity*. With SDM, the presumption is always in favour of the person with a disability who will be affected by the decision. A supporter provides options and assists in identifying the 'will and preferences' of the person requiring decision-making support ensuring they are reflected in a decision made by the person requiring support.

3.2   Article 12 CRPD and Legal Capacity

Key to supported decision-making is that a person at all times retains 'legal capacity'. CRPD article 12(1)(2) affirms this, and that a person has a universal right to exercise legal capacity on an equal basis with another. Legal capacity as it is understood in CRPD article 12, comprises two concepts traditionally separated in the general law:

1. 'Legal standing' – the status of being a person before the law, and

2. 'Legal agency' – the ability to act to enforce certain rights.

The general law conception of legal capacity is concerned only with agency and the ability of a person to make a decision. In combining them, article 12 is understood to mean that a person will always retain legal capacity, at least in the sense of retaining legal standing or status, and legal agency, even if they have a cognitive impairment that would require the provision of supports to exercise their legal capacity.

Thus, decision-making ability is not a necessary precondition for exercising legal capacity; in this way, article 12 has been said to have brought about a 'paradigm shift' in the way legal agency is understood and departs from the way it has been traditionally formulated and protected in law.

3.3   State of the literature

There is a lack of empirical research from Australia and Internationally as to what constitutes 'best practice' in SDM in the senses it has been distinguished above. Similarly, there is a lack of extant literature that focuses on operationalising SDM across systems. There is evidence that awareness of SDM is growing amongst states, and a number of international jurisdictions have undertaken reviews and reform of Guardianship and/or Mental Health legislation for example since 2006.

In Australia, research has been done on supported decision-making in the health, mental health, aged care and consumer transactions spaces by researchers at the Melbourne Social Equity Institute, the Melbourne Disability Institute, and Deakin University for example. The recent Cognitive Impairment Diversion Program (CIDP) operating in the NSW justice domain was regarded as successful, though it is not clear how such programs can be regarded as SDM, rather than something else. The La Trobe Decision-making Framework shows early promise as a best-practice tool to assist parties (including organisations) in developing capacity around understanding and implementing support for the process of SDM. The framework has been developed by the SDM project team at the La Trobe Living with Disability Research Centre. It is based upon a peer reviewed evidence base built up over a period delivering and evaluating capacity building programs for supporters and those requiring decision-making support. It is currently being adapted for use at the Queensland Public Trustee.

3.4   Supported decision-making is inherently good

The relative lack of evidence for the efficacy of SDM programs should signal caution when embarking upon a reform process. However, this should be balanced with acknowledging that the existence of the CRPD and its subsequent ratification by many states, indicates the global

community considers the pursuit of equal recognition before the law for all persons with disability to be inherently good.

3.5   Safeguards

A key area of concern in the literature is how best to protect people who require decision-making support from the undue influence of a supporter. This is identified as a particular problem amongst informal supporter networks (such as in a family where a support person may be a parent). In the absence of safeguards there is a risk SDM becomes a form of 'surrogate guardianship'. Capacity building for supporters focused on understanding 'human rights', developing reflective ability around the process of decision-making, and recognising biases and undue influence has shown some success.

3.6   Good practice principles

The most critical principle underpinning effective SDM is that there should be a long-term trusting relationship between the supporter and the person requiring decision-making support. The supporter should understand the potential power imbalance and comprehend the importance of the dignity of risk. The full list of principles identified in the desktop review are noted in Section 5.

4 Key findings from consultation process

The consultation process included representatives from disability organisations, human rights organisations, trustees and guardians, and the Commonwealth Government. The perspectives of people with disability were included via representative organisations, some of which consulted members in making submissions. Participants provided insights from a range of perspectives, including Aboriginal and Torres Strait Islanders, young people, people from culturally and linguistically diverse communities. Insights of supported decision-making ranged from day-to-day activities to more formal processes such as those used by trustees and guardians appointed through formal mechanisms.

This section summarises the key findings from the consultation process, including the key elements of decision-making (Section 4.1), the challenges and barriers to supported decision-making for different stakeholders (Section 4.2), capacity building required for each group (Section 4.3), and how supported decision might be improved (Section 4.4). This is informed by both focus groups and written submissions to the consultation process.

4.1 Key elements of supported decision-making

> It doesn't matter whether it's a big macro decision or it's a small one about the day-to-day activity, more it's about the fact that someone's actually making a decision or reflecting on it regardless of what it is. (focus group 4)

Stakeholders identified key elements of supported decision-making consistent with the literature. This included the importance of:

- Trusted relationships between the person and their supporter

- Supportive networks to support process and provide safeguards (ensure not isolated)

- Supporters who are flexible, allow time for the process

- Supporters who help explore options and help understand the consequence of choice, while allowing dignity of risk and learning to occur

- Supporters who support a person's will and preference, rather than impose own values or bias, or best interest

- Understanding and responding to communication needs, providing information accessible to the person

- Reflecting on the process, to learn from the process and review decisions

- Substitute decision-making being the last resort.

Stakeholders that had observed good supported-decision-making practice highlighted:

> Whether it's guardianship or any other legal entities … it still comes back down to individuals working in that system. … because people actually understand what the social model of disability is, what the whole of community approach is, what the holistic approach

is, enabling people to have the best life they can. Some people just innately get it, it doesn't matter what jurisdiction they work in, and do their best for that enablement for individuals, but generally it just doesn't happen. (focus group 4)

Example provided by one stakeholder consulted

Mum gets an A+ because she researches options to present to me, takes time to do SDM, goes above and beyond to find new opportunities, she did courses and training to learn how to do it.

Bad supporters don't listen to people or respect them. If SDM goes well the decision supporter should feel proud. Sometimes decision supporters' patience gets tested because the decision maker makes choices that they wouldn't personally make.

Good supporters slow down and go at my pace, not at their speed. Good support makes me feel safe, confident, listened to. Bad support makes me feel unsafe, uncomfortable, exploited, used to serve someone else's benefit, disrespected, not listened to. Good SDM gives me time to process. We know SDM has been good because of how we feel. We know SDM has been good because the decision has happened but that's not always the biggest thing. It's more important how the SDM process goes rather than just what gets decided. (submission 6)

4.2 Challenges and barriers to supported decision-making

While stakeholders agreed about the key elements of supported decision-making, they identified a number of challenges and barriers to operationalising supported decision-making. They related to the person with disability (in terms of individual needs, and individual networks), informal or natural supports (availability and bias), disability and mainstream services (time, skills and resources, policies and processes, risk aversion), and government (legislative basis) and society (in terms of attitude). Challenges may be experienced in day-to-day living, in accessing mainstream services such as health, education and justice, as well as specific supports related to their impairment. While mostly inter-related, they are discussed separately in turn.

4.2.1 For people with disability

Stakeholders highlighted that supported decision-making was not always a priority for people with disability, and that often 'survival' took priority – 'around care and food security and those types of things' (focus group 4). The key barrier to people with disability exercising their will, preference and rights, supported or otherwise, was perceived to be due to the 'low expectations that are put on people with disability' and the impact this has on people with disability moving forward (focus group 4).

Stakeholders recognised that barriers to supported decision-making for people with disability vary depending on individual needs and circumstances and vary across their life course. However, there were concerns expressed for particular demographics.

Young people

While children were not a primary focus of this study, stakeholders highlighted the importance of considering young people (up to the age of 25) and how they need to be supported as they transition from childhood (0–18 years old, where best interest principles apply) to adulthood (18

years and older, where will and preference applies), in a way that respects their evolving capacity. The point of transition may be challenging for both the young person, as well as their families, particularly when they have not 'had much opportunity to make real substantive and transformative decisions about their life' (focus group 6).

> We have parents and caregivers who are really interested in learning more, but we also have some who are incredibly protective of their children. (focus group 4)

There may also be additional considerations when 'transitioning from one system to another, or from a system out of the system' (focus group 1). Young people facing the greatest challenges were likely to include those who have not had access to mainstream education, or broader networks, and who rely on caregivers to help make the transition.

> For many children and young people with disability, their families and caregivers are their primary advocates and allies, but this isn't available to all children and young people and we need to ensure there are supports/arrangements in place for children and young people not living with their birth families and/or in institutional settings. (submission 10)

Young people with disability may not have access to mainstream education where understanding of rights and skills in exercising those rights may be learned (focus group 4), and therefore may rely on caregivers to help make that transition. Young people in institutional settings may be further disadvantaged if networks and supports are not available. Failing to help young people build capacity can have long-term consequences, whether they have informal supports or not.

> … they're then handed over to the Guardianship Board for the rest of their life because they have no capacity, but that capacity hasn't been supported or developed through no fault of their own, it's the system that's stopped them being enabled to be the best person they can. (focus group 4)

> … it can be really daunting and difficult, and for some people nearly impossible to start making decisions and then they fall into that guardianship world where their capability and capacity to make their own decisions may be a lot greater than what they're afforded. (focus group 4)

Women

Stakeholders identified prior studies highlighting the exclusion of women and girls with disability from decision-making processes, over and above their male counterparts. As one stakeholder highlighted:

> Women are systematically under-represented in decision-making processes that shape their societies and their own lives. It is widely recognised that women and girls with disabilities have fewer opportunities, lower status and less power and influence than men and boys with disabilities. (submission 11)

> If women and girls with disability are involved in the decision-making process, it is often done as an 'after thought', right before or even after the decision is made. This leaves women and girls with disability with insufficient time to understand and consider the information, choices and potential consequences of the decision or seek support from a trusted or independent source. (submission 11)

Lack of access to supported decision-making 'is particularly dangerous for women and girls with disability who are significantly more likely to experience domestic and family violence, meaning decisions are often influenced or made by those perpetrating violence and abuse' (submission 11).

A concern raised by a number of stakeholders was access to sexual and reproductive rights.

> For women with disability, a common example of 'bad supported decision-making' occurs around the use of contraception. While there are many contraception choices available, women with disability, particularly women with intellectual and/or cognitive disabilities, are often steered towards either long-lasting contraceptives … or encouraged to undergo sterilisation. While a woman may 'agree' to this, their decision is made without an informed understanding of the long-term consequences or the benefits of other available options. This is supported decision-making at its worst as it is often the result of pressure from family, carers, or medical professionals. (submission 11)

Additional challenges and barriers faced by women with disability also intersect with evolving capacities of young people, culture, and location (discussed in this section).

Regional and remote areas

In Australia, additional barriers arise in regional and remote locations due to lack of access to systems and services. As one stakeholder noted:

> The further you get out of metropolitan regions in Australia there's less and less support networks that might enable a person with disability to have that support and control in their life. So I think that's a big conversation in many communities that is not being had and that control is taken away from those individuals because it's the environment that's let them down because there's no further supports in their life. (focus group 4)

For example, in very remote areas, young people with disability may have to move away from home and into out of home care to access education (focus group 4).

Cultural considerations

Challenges may be different or more complex for people from **culturally and linguistically diverse** (CALD) backgrounds, particularly more recent migrants whose natural supports may be unaware of the systems and services available. This may be further compounded by different cultural conceptualisation of disability.

> Sometimes the role/value of people with disability often sees people with disability being denied any decision-making opportunities because it is believed they are not the best person/don't have the capacity to self-determine. … Many CALD communities have low expectations of CALD people with disability; shame/stigma associated with disability, religious/cultural explanations of disability, reinforce the belief that 'others' are to make decisions on behalf of people with disability. (submission 5)

Natural supports, due to lack of disability awareness or inclusion, and formal supports such as through settlement services may be absent or harder to access (submission 5). Rights of the person with disability may be poorly understood.

…there are so many issues associated with – and the wider community – around the person with disability's ability to self-determine, and provided with the opportunity … [to] make decisions that in that time and in that moment were best for them. But again, I think it just comes down to opportunities, the know your rights stuff, and creating cultural awareness, be it in your emerging communities and also in the wider community around people with disability self-determining. (focus group 4)

Culturally and linguistically diverse people may also have other support needs, including interpretation – the cost of which may be prohibitive to individuals and services (focus group 4). The role of interpreter may fall to family or friends who may enable or limit the persons engagement (focus group 4).

So the cost of ensuring that you're actually providing supports to meet the communication needs of the individual you're engaging with to truly understand the opportunities and to build the interest and engagement around the expectation that I want to be engaged in decisions about me, that stuff just doesn't happen easily. … this stuff has systemic barriers for new and arriving communities, for refugee communities and for people who have no or limited English proficiency. (focus group 4)

This is confounded by the lack of access to face to face supports and services.

[People] don't have access to people to have discussions. Everything's online, everything's via telephone, so how is supported decision-making practically going to happen through a professional sense when people aren't on the ground to deliver it be it formally or informally? (focus group 4)

Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Inlander peoples with disability also face both systemic, historical and cultural barriers to exercising their will, preference and rights. Stakeholders identified that due to mistrust, many communities were not well connected to services and systems. This may limit understanding and knowledge about those systems and making decisions about whether to access those systems. As a result, and as people with disability have not been 'allowed to progress at times to the full extent that they can as an individual', support and capacity building often falls to family members (focus group 4). As one stakeholder identified:

So, we would say there's a lot of enhancement to be done for people with disability to have the right knowledge around what supported decision-making means in their life or means in the life of their support networks which could be in a family or extended family or extended community. (focus group 4)

For some communities, people first needed help to achieve their cultural identity before being able to exercise their will, preferences and rights.

So, in [some] remote communities, particularly in the Central Desert, it's very important for teenage young men to go through the initiation process, and for young men with profound disabilities particularly, it doesn't happen. So, what happens there is if you don't go through that initiation process they never become a man, they stay in the family unit with the mother and the aunties, and they don't get to make their own decisions for the rest of their life, that's how the cultural tradition and protocols work. (focus group 4)

Barriers arising from diverse support needs

Stakeholders identified the need to ensure supported decision-making meets the needs of everyone who may need support making decisions, not just those with severe cognitive disability (focus group 5). Much of the focus of supported decision-making is around complex communication needs, who represent a very small proportion of people with disability. As one stakeholder asked, 'have we lost a bit of oxygen in the room to those really complex cases and not spent enough time on operationalising the others?' (focus group 3). There is a continuum, not just about the types of decisions that require support, but also the level of support required by an individual, such that support is proportional to both.

Supports also may be different for those with psychosocial disabilities.

> The supported decision-making conversations and building capacity are very different. I think that that's - to how that overlaps with the NDIS similarly there's a whole cohort of our clients who have been left behind by the NDIS and they're the clients with the psychosocial disabilities and they're difficult to fit into a bucket. (focus group 6)

For some, the first support required may be in supporting their shift to self-determination.

> There's a portion of our clients or cohort of our clients who have an element of learned helplessness because they're being institutionalised and we sometimes ring them up and we've been having this discussion even [before changing] the legislation, trying to promote "hey do you want to go in finance" – "no, I'm okay. You guys are doing it. I don't want the stress". (focus group 6)

> People who are isolated either due to lack of informal support networks or due to living arrangements or accommodation (group homes, homelessness, prison) are also less likely to benefit from supported decision-making processes (if there are any in place in that jurisdiction). (submission 2)

Overcoming systemic barriers

Stakeholders noted the 'further barriers' for people with disability being able to access education, health and justice due to the lack of knowledge and understanding by services and systems of their rights and the supports 'required to ensure a person's capacity to make an informed decision is facilitated' (submission 8). The challenges and barriers experienced by people with disability in exercising their will, preference and rights were often introduced by society, government, services, and formal and informal supports. This extended to exercising other human rights including education and reproductive rights. For example:

> [a supporter might object] to that person having reproductive rights because they would see that they [the supporter] would become the carer, rather than the sector supporting that person with disability having their capacity built to be able to be that mother or father to that child their self. (focus group 4)

Barriers may be contingent on location, in terms of the supports available. Barriers may also be systemic. An example was provided where there was an expectation that the family provides informal care for their child for at least part of the day; 24 hour care was only available if the child lived away from home such that the only way a family could access 24 hour care would be to have their child moved to out of home care and away from family (focus group 4). Removal from families

was also experienced by families living in remote areas when their child needed to attend an accessible school.

> Yes, they get to have an education and some form of supported decision-making in their life through that carer wraparound, but then they're taken away from country and culture so, you know, what happens in your life, and the deadly death mob will tell you this over and over again, you know, "When I was at school I either had to choose to be Aboriginal or have a disability, I cannot be both". So my Aboriginal needs can be met or my disability needs can be met. (focus group 4)

Challenges are higher for those without informal networks and informal supporters; however, some stakeholders cautioned against relying on informal supporters and the burden this places on families (submission 10).

> the reality is we [NSW] do not have a law supporting decision-making. What we do have is substitute decision-making which is based upon a best interest model. … We'll only appoint a substitute decisionmaker as a last resort. That's our legislative charter. (focus group 5)

The challenges and barriers experienced by people with disability in exercising their will, preference and rights may be impacted directly by informal and formal supports.

4.2.2 For informal supporters

Informal supports, sometimes referred to as natural supports, include family, friends and peers who provide support for decision-making. Stakeholders recognised some family members 'may be more useful than others' (focus group 2), some may reinforce dependency (focus group 3), while others had 'old-fashioned views about disability [and were] more protective' (focus group 6). Importantly, informal supports were 'not always aware of the influence they exert of the person they are supporting' (submission 1), while others were surprised when formal supporters encouraged or promoted the will and preference of the person, including their dignity of risk (focus group 6).

Stakeholders also highlighted that people with disability may be subject to undue influence from family members, limiting their will, preference and rights.

> There is no doubt that people with disability are subject to abuse, neglect and exploitation – hence our current Royal Commission. Such influence may come from a nefarious family member or friend or from a support worker. (submission 2)

Informal supporters may be a barrier to a person with disability exercising their will, preference and rights.

> Parents become, in my observation, quite rightly overprotective. They are making decisions right from the beginning. They are protecting. That's their job to be the protectors for their children, and if they have a child with particular vulnerabilities, their caring mechanism is amped up. (focus group 3)

Informal supporters may also themselves face challenges in supporting a person due to the information and support provided to them. For example, families may be told their child is 'not going to be able to attend the mainstream school', rather than being told how they may be supported to access education (focus group 4). Stakeholders identified a lack of training and resources for informal supporters 'to understand the benefit of the person with disability making

decisions for themselves and building their capacity' (focus group 1, submission 1). Further, training resources that were available were likely to be targeted at formal than informal carers.

> I've spoken to a lot of families who want to do – they've heard about supported decision-making and then they want to do it so they go looking for resources and they find this stuff that's just so wordy and complex and they're already time poor … they don't have time to sit through like a six module online thing or to read this thick document and do activity after activity … it's not for the everyday people that are making decisions and supporting decisions. (focus group 4)

Many stakeholders also recommended 'that people that are supporting the decision-maker are also supported' (focus group 6), and that services and systems did not over rely on informal supporters to fulfil this role.

> … a lot of the time the responsibility gets put back on the families … to be doing all the informal support, the decision-making, so we need to sort of safeguard that. And I know it's very tempting for government systems to go that approach because I mean it's cost efficiency, it doesn't cost anything to have people that are already doing that to do that better. (focus group 4)

4.2.3 For services

> All people use informal decision-making supports to make decisions in their lives. For example, we seek advice and guidance from friends and families regarding our finances and health care choices. Unfortunately, many people with disability lack the networks that provide this informal support, and other more formal arrangements may be needed. In more and more cases decision-making support is being provided through support workers, disability advocates or others such as community volunteers. (submission 2)

Support for decision-making may be provided by services in the provision of those services; support for decision-making may also be provided by a formal support outside of the general provision of services, such as from an independent advocate. This section discusses both forms of formal support, and how the challenges of each to the person being supported and the formal supporter.

Formal support for decision-making as part of service delivery

People with disability engage with a variety of services. Services may provide support for decision-making as part of service delivery. However, in their rush to get work done, service providers may not give people the time to help them make decisions (focus group 1). Sometimes the default or preference of services is to work with a substitute decision maker (focus group 1).

> Administratively and from a contractual point of view there's a desire to have a substitute decisionmaker's signature on all of that paperwork which really limits the ability for us to encourage whether you call it supported decision-making or encouraged capacity development within that very broad support framework that the NDIS provides.
> (focus group 1)

Services being a barrier to accessing will, preference and rights may be unintentional. As one stakeholder noted:

> I think an issue that the disability population really faces in the justice system is acquiescence, so that tendency to just say yes because you don't want to give a wrong answer. … you're just going along with whatever the professional is telling you is the right decision to make. (focus group 4)

Services may also face challenges in supporting a person in exercising their will, preference and rights, highlighting 'workforce training and development around supported decision-making remains inadequate .. to often based on a medical model of disability and lacks the human rights principles that support the rights and autonomy of people with disability' (submission 11).

> There is a risk adverse nature around decisions. People want something that they can feel confident it is a good decision and reflects the persons will and preference. Challenge to establish those standards in a proportional way and identify how that can be operationalised in a day to day way. (focus group 2)

> It's a big exercise to shift culturally that thinking. So, it's one thing for us to talk about what we can do or what the legislation might allow but you've also got all of those providers who have their own financial and other risks that they need to manage which influence how they view the world as well. (focus group 5)

This may be particularly challenging when working across jurisdictions or services.

> Our advocates work across jurisdictions. This in and of itself can prove challenging as whilst as an organisation we absolutely support the tenets of supported decision-making and the CRPD; we often encounter agencies that either do not understand supported decision-making or are extremely wary of it. (submission 2)

This may also be more challenging in specific contexts; for example, in the NDIS context, 'the roles of participant/parent/guardian/nominee are unclear' (submission 10).

> There are times when others who are cast with responsibilities, whether it's medical or legal or whatever, may seek to have that certainty. The problem is when that search for certainty is the default position. (focus group 3)

While incorporating support for decision-making into services was considered important, some stakeholders also identified limitations to the process of supported decision-making in the context of service delivery.

> I think the only way you can know someone that well is if they're a family member, an immediate family member, who you've lived with and seen in action pretty much the whole time. So I think that the intent is great. I think the practical application of that is very, very impossible. (focus group 6)

Others highlighted concerns about the process.

> Simply putting statements in the first person saying that he said this and he wanted this, that is not supported decision-making. That's when it becomes a furphy and quite frankly dangerous because the reality is people are imposing their will… (focus group 5)

One trustee suggested that 95% of interactions were by phone or email, the remainder in person, with often little continuity between the service and the client – other than highly complex cases – often due to staff turnover (focus group 6). Another stakeholder added:

The increase in centralised processes and their virtual nature make it difficult for people with additional communication needs to be able to interact with systems using their preferred communication method. Many interactions are completed online using email or phone. This results in representative decision makers being appointed, communication is then undertaken with the representative. Example: person who communicates with eye-blinks was appointed a nominee because the system was not flexible enough to adjust how it communicated with this person. This person was able to make their own decisions. (submission 1)

Combined, this highlighted the need for separate formal supports for decision-making proportional to the decision being made. Proportionality requires supports for decision-making for people with disability to ensure they are on an equal basis with others. This recognises all people may rely on support for making some decisions, and may be vulnerable to coercion and undue influence in this process.

Formal support for decision-making outside of service delivery

The availability of formal supports for decision-making, outside of service delivery, may be limited – especially for specific cohorts with specific needs. As one stakeholder commented, 'very few organisations across Australia have the skills/expertise/resourcing to provide quality supported decision-making supports' (submission 5). As a result, individual advocates were more likely to respond to crises rather than undertake the long-term transformative supported decision-making required (focus group 4, submission 5, submission 10).

Disability advocacy organisations … as a result have to triage need by level of crisis i.e. violence/abuse/neglect, income support, homelessness issues are prioritised over access to or participation in employment/education, etc. (submission 10)

While there has been some investment in building capacity for both formal and informal supporters, stakeholders said that fragmented investment in short-term supported decision-making pilots has failed to lead to the transformative change required.

There's nothing ongoing, there's no continuity. These things get developed, they get tried out and then as soon as they've got some learnings the money runs out and it ends up on some dusty shelf, or the role isn't funded anymore and people move on to other things. (focus group 4)

One organisation was seeking to learn from the pilots to further develop practice:

[we are] trying to track down project teams that worked on them and what they learnt… there's so much there in the grey literature and just sitting in peoples' heads that hasn't been tapped into. I think when you look only at peer reviewed academic literature on supported decision-making, you're just looking at this tiny slice at the top. (focus group 4).

4.2.4 For government and society

There are a number of systemic barriers to people with disability exercising their will, preference and rights – due to both the legislative framework systems and services operate within, as well as attitudes in society.

The lasting legacy that Mungo Man out in Lake Mungo was a one-legged man that participated in a hunt because it was about being included so our people usually included people**, it was systems that separated and imposed other ways of doing business**. So when you take away lore, for communities you end up with the jumble that we have. Disability's been around for ever and ever and people were included and participated, **it's legislation that separated those values**. (emphasis added, focus group 4)

Legislative barriers to supported decision-making

Each jurisdiction is bound by different legislation and is operating within their own legal framework. Stakeholders identified inconsistencies in policy and practice that impact on service delivery – particularly where jurisdictions overlap, such as through the NDIS (submission 2). While a uniformed approach was desirable, stakeholders also recognised the difficulty in achieving this (focus group 5).

> [it is important] to acknowledge the guardianship and administration systems across the country and their very specific roles in some of these decisions. … it's difficult for the Commonwealth to get everyone to get in line and some jurisdictions don't want to take a step backwards and others don't want to step up. (focus group 5)

This difference in legislation was clearly evident in **guardianship and trustee** processes across the country, which appoint substitute decision makers but also recognise the benefits of making decisions reflecting will and preference. While some jurisdictions aspire to will, preference and rights in their practice, being more representative than substitute decision-making, they are ultimately 'bound by the legislation' and must exercise reasonable care and be accountable for decisions.

> The appointment of administrator is still in Victoria an appointment of a substitute decision-maker. There's an attempt to bring in supported decision-making style concepts but at the end of the day it still is a role that can make a decision on behalf of someone.
> (focus group 6)

Not complying with the legislation 'puts those entities at great risk if somebody wishes to challenge the decisions that they're making', such as an aggrieved family member (focus group 5).

Ultimately, trustees and guardians may remain the final decision maker – but there are a number of states and territories that are encouraging individuals to be a part of the decision-making process and build their capacity in the process (focus group 6). This 'hybrid' approach raises a tension between will and preference and best interest principles that ultimately needs to be tested through legal processes.

> I believe in the majority of Australian jurisdictions still whilst they obviously are required to take on the views of the person and where possible put those into effect from a legal perspective if the assessment of that appointed substitute decisionmaker is that in fact the person's will and preference or views is not in the best interest of that person then they're duty bound to follow the best interest decision. That's where the tension arises. (focus group 5)

There are also barriers to supported decision-making introduced through conflicts between (or failed recognition of) other legislation; for example, between trustees and guardians and the NDIS.

> The NDIS [is] a regime that doesn't necessarily gel with the state based appointment regimes… effectively there are different hats that you would have to wear - see the NDIS expects that for it to exchange information for example with a third party that person has to take on a nominee appointment. They won't recognise an administrator as of right. They're perhaps better at recognising guardians as of right but that's a whole different space in some ways. It leads to a very clunky interaction from our side with that legislation in that we're often shut out of the knowledge of the information relating to our own client's entitlements, even whether or not they're applied, whether or not they've been granted et cetera. (focus group 5)

Further, the introduction of new legislation and processes has created greater need for supported decision-making, which, in the absence of supporters has led to an increase and reliance on substitute decision-making.

> If you talk to the Public Advocate Victoria they're being asked to be involved more and more for NDIS related matters which is totally counterintuitive. It's just contrary to the intent of the NDIS to have a supported decision - a substitute decision-maker because there's no network or framework in place for those informal supports. (focus group 6)

Attitudinal barriers

There remain attitudinal barriers to people with disability exercising their will, preferences and rights. Whether this be people who support people with disability directly (informally and formally) as well as society more broadly. As one stakeholder said:

> The largest barrier to supported decision-making is attitudinal. Be it from well-meaning family members or from government agents. This is grounded in societal low expectations of people with disability, and reinforces notions of "lack of capacity". (submission 2)

Without addressing attitudinal barriers, including how they are translated into legislation and policy, services and systems, low expectations may continue and transformation may be limited.

4.3   Capacity building required

As part of the consultation, stakeholders were asked to identify what was required to build capacity to deliver the key elements of supported decision-making, to strengthen supported decision-making and overcome many of the challenges and barriers identified. While capacity building was considered in terms of different stakeholders involved in the process, there were a number of common themes arising, including the need to co-design information resources and tools, the focus on the process not just the outcome, the need for time and resources to do it properly, and the transformative process required.

> The process is much more important than the type of decision, and when people make small decisions then they get better at it and then they can make bigger decisions and it's a natural progression rather than trying to impose "This is how you make a small decision and this is how you make a lifechanging decision". (focus group 4)

People with disability need to understand their rights, supporters should understand how to provide support and be aware of their limits, and services need to understand the role of supporters (focus group 3).

4.3.1 For people with disability

Capacity building is part of the process of supported decision-making. However, many people will require support and information to start this process – particularly if they are or have transitioned from a best interest model.

> there's part of it that's around working with families and parents and caregivers, and there's part of it that's working with young people around sort of navigating that transition where families have had decision-making authority, for want of a better term, and they have been using that best interest framework and now it's time for increased independence, whatever that looks like for the individual, and how they navigate that together and build that capacity… One of the things the NDIS can do is support young people to have that independence and to be getting support from other places so that there can be sort of parent or family roles that aren't all encompassing. (focus group 4)

Stakeholders suggested peer networks were a useful source of information and support.

> Peer-led examples where [people with disability] have made decisions by themselves can chat to other[s] about the benefits of being engaged in a decision-making process. … peer-led or if it was driven by civil society organisations, would have the best possible chance of getting the outcomes which is building independence and capacity to be more confident and comfortable and making decisions and the families respecting those decisions. (focus group 4)

However, it was acknowledged that some people may not have access to peer networks due to various informal and formal segregated practices (focus group 1), and may miss out on learning from others, as well as the safeguards offered by peers (discussed in Section 4.4.3 below). In which case, the first step to building capacity may be encouraging people with disability to access peers.

The process of supported decision-making may be different for everyone and stakeholders highlighted the need to understand how each individual 'would like to be supported and if they would like to change the way they are being supported', recognising 'many people will require capacity building to get ready for decision-making support' (submission 1).

> Often the terms 'decision' and 'decision-making' are not understood and many people have had very limited experience being involved in decisions that affect their lives. (submission 1)

Such capacity building must be clear about what supported decision-making is, and is not, and recognise that it, itself, is about 'building capacity – allowing safe mistakes to occur, to allow learning' (focus group 1).

Capacity building must also be sensitive to historical and current factors affecting the relationship between communities and government/services.

> Particularly for the Aboriginal and Torres Strait Island community, there's a lot of mistrust in the sector because we all know the reasons …. for our communities culturally they feel more trust and safe when they can come together collectively and share these conversations … but it belongs to the community. [Others] need to get permission to come into that space and share that information, so the community and the person with disability has the control. And then, you know, what happens in these spaces, if there's a lack of understanding with that knowledge transfer, whether that's because of language or cultural

differences or just general education around what things mean, collectively the community share that conversation when they're in a safe place. … art and culture is so important, it's first and foremost for our communities in finding that safe place and talking about what their needs are through storytelling and art.

Capacity building may include a range of mechanisms to support someone in identifying their will and preference.

So for an example, I can give you a young person had non-verbal communication, had no control in their life what happened in their life, what their mother did was started art boards for the service sector to understand what the needs were and, you know, how this young woman could control her life what was happening daily in her life, so it's all done through art storytelling, and this allowed that young girl to then be in control of her life. So over a period of time, the mother would put up certain storyboards around what was happening that day in her life … and if the daughter didn't agree with it then she could tell her mother and she would take down the storyboard. … And then she learnt to put the storyboards up herself. (focus group 4)

The supports needed by people with disability to build their capacity in supported decision-making will vary; further, they may need access to resources, including specific funding in their NDIS plan, to support this and then opportunities to build their capacity over time (submission 6). For many people with disability, this will ultimately lead to 'confidence in decision and ability to inform others around them of confidence or certainty in decision/s…. [and a] higher chance of other people (family/friends) supporting/recognising decision' (submission 5).

This process may also benefit from building the capacity of informal supporters to recognise, support and enable this transformation.

4.3.2 For informal supporters

For most people caring for a person with disability, they do it the best way they can, not knowing what the appropriate practices may be. They may be doing it the wrong way at times, but that's because of lack of knowledge in regards to how to care for individuals appropriately. (focus group 4)

Given the availability of informal supporters, stakeholders considered the need to 'harness and strengthen natural supports' (focus group 2). Capacity building is required to help informal supporters support people with disability, and also ensure they understand and safeguard the rights of the person while also minimising risk to themselves (arising from conflict of interests, focus group 3). Given informal supporters often have had a long relationship with the person with disability and have their trust, they are often best placed to support a person in building confidence to make decisions. However, informal supports may be a barrier to realising will and preference (identified in Section 4.2 above), or simply need to 'readjust their own expectations and understanding' (focus group 3).

I think the vast majority of families that are caring for their loved one is because they want to help them, and most people do want their children and their adult children to grow up and be independent. … I've had family members say to me I want to do that, how do I do that?", but they don't know how and no resources, the tools, the services, are not accessible and they're not there. (focus group 4)

Stakeholders suggested that information resources and training need to be simple, brief and appropriate to their needs, including culture, reflecting the time they have to build their own capacity (submission 6).

> I think we need to develop programs for our communities particularly to understand what this means in a mainstream context, how do we develop it to work in the context for our communities particularly in rural and remote regions. (focus group 4)

Stakeholders highlighted the need for informal supports to understand the rights of the person with disability, and to help them exercise those rights, and reflect on how this process occurs (submission 1).

> There is that process of developing decision-making skills and developing agency and families stepping back. (focus group 4)

4.3.3 For services

Consistent with the key elements of supported decision-making identified in Section 4.1 above, stakeholders consulted identified a number of areas to build capacity in services – both disability services and other services, and both organisationally in terms of systems and processes, and in individual professionals – to improve supported decision-making.

For some, stakeholders highlighted that contact with services may provide opportunities to access supported decision-making. Supported decision-making should also be accessible to those in institutional settings (submission 10).

> It's a horrible environment but the institutional nature of it probably provides an opportunity for some of the formal supported decision-making work that you're not going to get in a family environment necessarily. (focus group 4)

However, services need to develop their understanding of the rights of people with disability and how they may exercise their will, preference and rights – and support them in doing so. To do this, stakeholders suggested organisations (disability services or other mainstream services) need systems and processes, and safeguards, in place to identify when someone may need support, how that support may be provided, and recognition of the role of supported decision-making (submission 1).

Stakeholders identified the need for greater training, including awareness raising, of personnel across systems; for example, in the justice system, training of police, lawyers, court officials and judicial officers 'to ensure a person's capacity to make an informed decision is facilitated' (submission 8). Stakeholders also identified the need for professionals to have access to evidence-based resources, not just for themselves but also for the person with disability and their families (submission 1). Resources should relate to the rights of the person with disability, the role and recognition of supported decision-making, understanding the level of support required, understanding the dignity of risk, and safeguards to protect all parties (submission 1, focus group 1).

For professionals in roles where support for decision-making is likely to be a significant part of their work, specific capacity building may include identifying options, communicating options, and

understanding cues that may be used to express will and preference (including signs, facial expressions, and behaviours) (submission 6).

4.3.4 For government and society

As noted above, many stakeholders commented that the term supported decision-making was unfamiliar to most people and only understood by a small number of professional advocates (focus group 4). This is not to say that supported decision-making is not occurring already.

> People don't know the term, people don't know that it exists, people have not even thought to describe the process of making decisions, that's just part of what they do as a mother or as a brother. (focus group 4)

Stakeholders also highlighted that the rights of people with disability, and the right to supported decision-making, may also be poorly understood and a cultural shift was required.

> You've got a societal issue, a devaluation of a group just because of a diagnosis that's at play as well, that feeds into those pieces that actually connect with that family unit of how this person will respond. So, when we're talking about capacity building, it's so much broader isn't it than the service system, the families… It's all of those connecting points, and the reframing of how they see somebody with a disability as far as they're equal and their place within community. (focus group 3)

> If we want to see a cultural change where people with disability are making decisions and they're being well supported by paid or unpaid supporters to do so … people need to know that it exists. I think most people would agree that it's an important thing, but they don't know where to start with it and everything seems quite inaccessible. (focus group 4)

While stakeholders identified the need to increase the awareness of rights and self-determination, the way those rights may be exercised may vary depending on jurisdiction within Australia. However, a better understanding of how rights can be supported may lead to less people coming under guardianship. As one stakeholder noted:

> There's so many mechanisms now for having different types of decision-makers and supporters appointed. It's not necessarily that easy for a layperson to weave their way through but with some guidance there would be probably – if there were more emphasis on those mechanisms that would take some of the burden off the more formal mechanisms of having to go through the tribunal and so forth to have people put these things in place themselves. (focus group 6)

4.4   Improving supported decision-making processes

A key issue for many stakeholders was a lack of understanding about what supported decision-making is and what it means in practice (focus group, submission 10). Others highlighted that while improving the process requires additional resources (focus group 5, 6), they believed 'it's really going to improve the quality in what they do and the quality of experience of their clients' (focus group 5). Operationalising supported decision-making requires a significant shift, starting with a change in culture. It also requires mechanisms to measure whether change is effective, and safeguards in place to ensure the rights of persons with disability, as well as protecting the supporter whether they are formal or informal.

4.4.1 Changing culture

A common theme identified by stakeholders was the need to change culture – regardless of policy. Everyone has legal capacity and should all have rights and act on rights; some people require supports to exercise those rights – and those supports should be proportionate and free of undue influence, coercion, etc. This requires an attitudinal shift in broader society and specifically services and systems to recognise the capacity of people to make decisions and support those that need support to make decisions. Importantly, concerns were raised about people 'who think they are doing the right thing … but are limiting [the person's] choice as it is easier or better' (focus group 1). In addition to better understanding will, preferences and rights, stakeholders identified the need to better understand what good supported decision-making looks like and promote and encourage formal and informal supports, and services more broadly, to recognise this process.

While support for decision-making may be provided by informal and formal carers for people with disability, stakeholders considered it critical to ensure other professionals providing services (including health, justice and other services) understand and recognise the need for and process of providing support for decision-making. This may extend to other ways of capturing decisions, such as easy read consent forms and video consent (focus group 2).

4.4.2 Measuring success

Many stakeholders recognised the need to, and difficulty in, identifying and measuring success in relation to supported decision-making. This might be different 'depending on which system you are looking at', and the need to look across systems and at each system; for example, the interaction between the NDIS and mainstream systems (focus group 2). One stakeholder suggested the Australian Health Standards Commission may be a starting point to identify possible measures of success. However, stakeholders identified the 'need to understand what success looks like for people with disability. Should be talking to people that need the support to understand what they want' (focus group 1).

While the ultimate indicator may be that will and preference have been exercised, it may be easier to examine indicators where supported decision-making has failed and seek greater understanding about the cause for this failure and how this may be reduced over time (focus group 2). For example, in a trustee setting, outcomes may include a decrease in the number of complaints, a reduction in errors (compensation paid), as well as more positive interactions with clients (focus group 6). Organisations may record also instances where they have overridden a persons will and preferences and why.

Whether measures focus on success or failure, measures should relate to both the process as well as outcomes for legally recognised and other forms of supported decision-making. When reporting failures, they should be active measures to report what has been actioned as a result (focus group 3).

Given the difficulty in measuring decision-making at a decision or individual level, measures of success may include measuring changes in attitudes and changes in understanding of supported decision-making by people with disability, informal supporters, professionals and services, as well as the broader community. This recognises that 'empowerment is ongoing' and that supported

decision-making is 'not just a singular decision that was made or the outcome' (focus group 5). This approach would also capture whether improvements to supported decision-making processes were making a difference – from day to day to significant decisions (focus group 1).

There is a risk that a policy focus on supported decision-making could lead to perverse outcomes. As one stakeholder said:

> My great fear though is that in the great rush to start labelling everything as supported decision-making we in fact go back in time because what we start doing is calling something supported decision-making when it's actually substitute decision-making and that is actually more than likely harmful. (focus group 5)

This could be minimised by also encouraging people to report on substitute decision-making and other forms of decision-making, recognising that for some, substitute decision-making – based on very different principles and standards of decision-making – may still be required.

For measures to be credible, they should be monitored, reported and evaluated independently (submission 2).

4.4.3 Safeguards

Most stakeholders recognised the **need for safeguards to minimise risk and prevent abuse** – and to make people aware of the risk – whether it is supported decision-making, or other forms of collaborative decision-making (focus group 5). Safeguards relate to **safeguarding a person's ability to exercise their legal capacity**, and to **ensure that the person requiring decision-making support has their 'will, preferences and rights' actually recognised and acted upon.** This may include ensuring a supporter is aware of potential power imbalances, and the possibility for undue influence, and they have the skills and support themselves to reflect on this. A key challenge is how to best demonstrate that a decision made by a person requiring decision-making support is in fact a decision of that person. While stakeholders agreed on the need for safeguards, there was some discussion about how this may work in practice.

> Given that supported decision-making operates both formally and informally, and operates on the minutiae of daily decisions right through to those critical legal decisions, how do we operationalise that, yet safeguard it as well? I mean, for me that is the greatest complexity, is teasing out the proportionality of all of this. (focus group 3)

Stakeholders agreed that circles of support or informal networks offered a level of protection (focus group 2) – the risk being where there is only one person involved who has no **oversight** (focus group 2), or where a person lacked informal support networks due to their living arrangements (for example, group homes, homeless, or prison; submission 2). As most people are engaged in a service or system of some sort, likely to have in-built oversight, many thought that most people would have some level of safeguards provided through services – although there is evidence indicating this is not always sufficient.

Some suggested professionals should be trained to **recognise undue influence and coercion**, to increase oversight, particularly for highly vulnerable individuals (focus group 1, submission 11). One stakeholder said 'specific attention must be given to the risks of coercion… to mitigate the higher risk of coercion faced by marginalised groups' (submission 11).

Stakeholders also recognised the importance of safeguarding supported decision-making processes (focus group 5) and using safeguards proportional to the decision being made (submission 1) including review mechanisms about the outcome and the process (submission 2, submission 6). In more formal supported decision-making processes, through trustees and guardians, in addition to operating within legislation, some used structured decision-making frameworks which included mechanisms of oversight and review (focus group 5, focus group 6).

In organisational settings 'systematising is compulsory' to manage risk; organisations active in supported decision-making 'need to be able to systematise supported decision-making and record or capture will and preferences' (focus group 6). As one stakeholder noted:

> What that's resulted in in some cases is a little information bucket in our systems where we can record what people tell us about what's important to them. We've made significant backend changes to support this new legislation. We kind of had to, to demonstrate to anyone that we were actually complying with what our clients wanted. (focus group 6)

As processes become systematised, they may become more accountable and easier to measure and report on (focus group 3).

Specific safeguards may need to be developed to ensure people are able to exercise their rights, access supports to exercise those rights, have dignity of risk, and have legal recognition of the outcome of the process (focus group 5, submission 2).

> Formal legal recognition of supported decision-making would legitimise and normalise this form of support in the community, and across the full spectrum of decisions to be made, and situations in which they are made. Where an individual has in the past had their decisions undermined or refused because of institutional concerns around risk or liability (such as by a financial institution, or health care professional), the role of supported decision makers may help to ensure that the individual's decision is respected in these circumstances. However, the appointment of a supported decision maker must not be overly prescriptive in that it undermines the rights of the individual. It must not lead to an assumption that a supporter need be appointed for a decision to be legitimate. (submission 2)

Safeguards need to ensure the person who needed support is still making the decision, and that they have not been subject to undue influence by the person supporting them (focus group 5). One stakeholder added, in their state:

> … there is no such legal concept of supported decision-making so the test would be whether the person themselves made the decision or otherwise. (focus group 5)

Safeguards need to also recognise collective decision-making, reflecting the 'cultural and social context of decision-making' and that 'sometimes it just happens differently for people and that's part of their decision-making identity' (focus group 5).

Some stakeholders identified a risk in supported decision-making being embedded in supports and services, suggesting it should be independent of services – therefore the safeguard being the independent provision of support for decision-making (submission 6, submission 11). However, this may differ depending on the person and the decision.

While education is needed for informal supports such as parents, family, and carers to understand and facilitate good practice supported decision-making under the right circumstances, DPOs and independent advocacy supports should be viewed as the preferred safeguard for people with disability. (submission 11)

In the process of safeguarding supported decision-making and the exercise of rights, some identified other potential risks. For example, 'if something is substitute decision-making it should be labelled such' (focus group 6). This would protect the integrity of supported decision-making and recognise that there remains a need for substitute decision-making, determined on a case-by-case basis through legal processes. If safeguards are 'over done', and supported decision-making is over systematised, it could also lead to an 'assumption that all decisions should be supported or made for a person' (focus group 1).

Ultimately, any safeguards (whether policy or legislation) 'must not be restrictive in terms of the means and modes of supported decision-making.' In terms of legislative processes:

Legislation should, however, provide parameters around the role of decision-making supporters, and safeguards to prevent undue influence and abuse including a conflict resolution mechanism. (submission 2)

Any change to legislation to incorporate supported decision-making requires time and resources to implement. One trustee estimated that conversations with clients took 25% longer when identifying will and preference (focus group 6). Legislated settings also benefit from being able to test the legislation (decisions) through formal mechanisms such as administrative tribunals and courts (focus group 6). Such recourse may not be as clear or accessible in other settings.

It takes time for the impact of new legislation to be fully appreciated. For example, Victoria introduced the concept of overriding will and preferences when it would cause serious harm, with serious harm is not fully understood and needs to be tested (focus group 6). The NT is currently reviewing their 2016 legislation to make improvements (focus group 5). Qld trustees has introduced 'structured decision-making' based on the La Trobe model to 'encourage more collaboration, not only with the customer but with their support network as well' (focus group 5); however, as a fiduciary, best interests can sometimes override will and preference where there is a very good reason to do so.

4.5   Summary

The data from the consultations were used to further develop the Principles and Guide (Section 5) and provide considerations for their operationalisation (Section 6).

5 Principles and Guide

This section presents the *Principles and Guide* on support for decision-making, drafted to be a standalone document, compliant with the CRPD. Section 5.1 provides an introduction to the Principles and Guide and how they were developed. Section 5.2 identifies the key elements of good supported decision-making, while Section 5.3–5.6 identify steps to transform, strengthen and support decision-making across government and society; organisations, services and professionals; informal supports; and person making decisions. Background reading on supported decision-making, developed as part of the consultation exercise, is presented in Appendix A.

5.1   Introduction

This document, the Principles and Guide, outlines the key principles of supported decision-making – perhaps better understood as the process of decision-making support – and how they may be implemented based on the national principles established by the ALRC review.[2]

Principle 1: Every adult has the right to make decisions that affect their life and to have those decisions respected.

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

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

Principle 4: Decisions, arrangements and interventions for persons who may require decision-making support must respect their human rights.

Recognising that detailed frameworks already exist, the purpose of the Principle and Guide is to: (1) identify steps stakeholders can take to operationalise and improve supported decision-making, and (2) identify the outcomes these steps are expected to achieve. Stakeholders are:

- Government and society
- Organisations, services and professionals
- Informal supports
- Person making decisions.

The Principles and Guide is designed to be intersectional, responsive to the needs of different demographics, including First Nations Peoples and culturally and linguistically diverse communities, LGBTIQA+ community, and are person-centric and person-responsive in their application.

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[2] Australian Law Reform Commission (ALRC) (2014) *Equality, Capacity and Disability in Commonwealth Laws*. ALRC Report 124.

Co-design with people with disability must be a foundational element to implementing the Principles and Guide to ensure relevant and accessible information, training and supports, so that they identify key facilitators and barriers.

The Principles and Guide were developed based on a desktop review of national and international practice of support *for* decision-making programs, studies, and activities, and supported decision-making legal and policy frameworks and guides. The findings from the review were further developed in consultation with key stakeholders. The pivotal role of supporters (both informal and more formal arrangements) was consistently identified to identify the will, preferences and rights of a person requiring decision-making support, uphold the person's rights, and give effect to the expressed will and preferences of the person requiring decision-making support.

5.2   Key elements of good decision-making support

In Australia, there are still mechanisms in place for substitute decision-making, many of which also accommodate or reflect the key elements of good decision-making support identified below. Three broad propositions are important to keep in mind: first, substitute decision-making is regarded as a 'last resort' in Australia. Second, it is widely held among Australian service agencies and law reform bodies that substitute decision-making can give effect to the will and preferences of a person with cognitive disability (at least to some degree and in some contexts). In other words, substitute decision-making should not automatically imply that a person's will and preferences have not been considered, and that a decision does not reflect this. This is particularly relevant for situations where a person may appoint another to make decisions for them under some arrangement. Finally, simply because a decision was made for a person by an agency or person does not mean that the agency or person was acting in the capacity of a substitute decision-maker. This is particularly relevant in some Trustee contexts.

The following key elements of good decision-making have been developed to be compliant with the CRPD and relate to decision-making support in general.

1. The person needs an established trusted relationship with the supporter to ensure the supporter understands the person's rights and is responsive to the expression of a person's will and preferences.

2. The person needs a broad supportive social network to assist them to make decisions, provide wider contextual opportunities for choice and decision consideration, and provide mental health support. The person needs adequate support to develop that social network.

3. Supported decision-making, as envisaged by article 12 of the CRPD, will require a supporter to:

    a. Recognise the person requiring decision-making support is capable of decision-making

    b. Have a positive attitude towards risk

    c. Recognise the importance of choice and control

    d. Uphold the rights of the person requiring decision-making support

    e. Provide support for decision-making that gives effect to will and preference. , and

     f. Identify and pursue opportunities for the person to make decisions and to encourage repeated exercise of rights, will and preference.

4. To ensure a person has their will and preferences acted upon, the supporter must be aware of their unequal relationship with the person they support and suspend their own judgments.

5. To communicate concepts in a way they can be understood by the person, the supporter must be aware of the person's specific support and communication needs.

6. To identify the will and preference of the person, the supporter must have the capacity to understand how the person requiring support expresses themselves (verbally and non-verbally).

7. In the case of a person with a traumatic brain injury or degenerative onset of cognitive impairment, or impairment that is episodic in nature, supporters should understand the person's will and preferences prior to the need for decision-making support.

8. The supporter may be required to anticipate and manage the potential emotional impact on the person and the process of decision-making.

9. To ascertain the person's will and preferences and give effect to them, the supporter must develop skills and approaches.

10. The supporter must understand the *process* of supported decision-making is paramount. The supporter must reflect on the process with the person requiring decision-making support, encourage transformative changes, and adjust their support to reflect the changes.

5.3 Government and society

5.3.1 Steps to transform supported decision-making

Legislative reform, including guardianship and financial administration, legislation:

- To recognise all people always retain full legal personhood and legal capacity regardless of disability or other cognitive impairment. Embed dignity of risk concepts in all relevant legislation and systems.

- To limit liability for a person acting in good faith, and following good practice, when supporting a person who requires decision-making support. Balance dignity of risk with potential liability to an agency, person, department and other supporters, including recognition of the duty of care, as articulated in the Disability Standards, NDIS and Quality Safeguards Commission. Supporters have a responsibility to find out what good practice is.

- To identify and provide guidance on the key duties and responsibilities of formal and informal supporters of a person who requires decision-making support.

- To recognise any orders and decisions made for a person via substituted decision-making process are limited to the defined matter and the defined time only and are not indicative of the person lacking legal capacity.

Policy reform:

- To embed supported decision-making processes as a preferred framework for interface in contexts where people who need decision-making support may interact, including justice, physical and mental health, child protection, housing and education.

- To develop and share a whole of government approach, policy and procedures recognising the primacy of supported decision-making processes and promoting consistency in implementation of systems of change.

- To develop whole of government policy and procedures to recognise people who require decision-making support, recognise their existing supporters, provide access to a supporter if needed, and recognise all decisions made through the supported decision-making process.

- To build capacity of public, private and non-profit sectors for supported decision-making as part of the National Disability Strategy for all outcome areas.

- To provide tools, resources (including wide-reaching capacity building and means of communication) and funding available to exercise supported decision-making.

- To establish safeguards in proportion to the decision-making process and the outcome – this includes the type and duration of decision and review process to check whether decision reflects the will and preference of the person and is the best interpretation of will and preference and respects their rights.

- To provide funding to ensure systemic and organisational safeguards for the integrity of the decision-making process, safeguards to protect the rights of the person with disability, and safeguards to protect the supporter acting in good faith.

Social reform:

- To provide information and education about supported decision-making for people with disability, their supporters, and the wider community to ensure everyone knows the rights of people with disability. This should also identify the facilitators and solutions to barriers (including cultural barriers) to supported decision-making.

- To establish regular feedback mechanisms, including consultation, with key stakeholders to understand system responsiveness.

5.3.2 Anticipated outcomes

- Increased understanding by society and across all government agencies of the concept of supported decision-making and how to facilitate the process.

- Increased expectations that people with disability have the right to make decisions about their lives and have the opportunity to be supported to exercise their rights.

- Increased control for people with disability about how they make decisions.

- Improved and consistent processes across governments to understand and respond to the will, preferences and rights of persons with disability.

- Contributing to the outcome areas of the National Disability Strategy.

- Increased support for supporters.

5.4   Organisations, services and professionals

5.4.1 Steps to strengthen supported decision-making

Build culture and capacity of organisations to support decision-making:

- Build the organisational and professional culture to provide the foundations for supported decision-making processes. Provide adequate resources (for example, staff time) to implement supported decision-making.

- Build capacity of staff by providing ongoing professional development for staff, from awareness of obligations to detailed knowledge of how to support decision-making.

- Provide information resources for staff, people with disability and their supporters about supported decision-making.

Develop organisational policies and processes to facilitate supported decision-making and to support people with disability and their supporters:

- Identify where and when supported decision-making processes are currently being provided or may be required in the organisation. Ask the person if they require decision-making support and how they would like to be supported, including if they would like to change the way they are supported. Use of a range of mechanisms to help person communicate their will and preference that is proportional to the decision being made.

- Identify supporters, including peer networks, family and friends, who provide decision support for a person.

- Guide the supported decision-making process, using a stepped framework so that the appointed supporter focuses on the person's will and preferences, and rights at all stages.

- Provide oversight mechanisms and safeguards to protect the person with disability and the supporter.

- Train staff to support decision-making, including how to support the development of the person's capacity to make decisions and understand the impacts of decisions.

- Ensure the integrity of supported decision-making by upholding the will, preference and rights of the person with disability, even when this conflicts with the preference of the organisation or supporter.

5.4.2 Anticipated outcomes

- Increased understanding of supported decision-making and how to facilitate the process.

- Organisations and supporters are confident and competent to provide supported decision-making supports consistent with the national principles.

5.5 Informal support

5.5.1 Steps to strengthen supported decision-making

The informal supporter needs to acknowledge their responsibility to:

- Recognise the person requiring decision-making support is capable of decision-making

- Have a positive attitude towards risk

- Recognise the importance of choice and control

- Uphold the rights of the person requiring decision-making support

- Provide support for decision-making that gives effect to will and preference. , and

- Identify and pursue opportunities for the person to make decisions and to encourage repeated exercise of rights, will and preference.

The informal supporter needs to:

- Develop their relationship with the person supported to ensure they understand the rights of the person and be sensitive to the ways a person expresses their will and preference.

- Identify other key people who have roles and resources in the supported decision-making process and seek their advice if required. This may include other family members, friends and peers.

- Identify facilitators and solutions to barriers to supported decision-making, including communication needs, cultural needs, environmental context, individual needs, and safeguards.

- Provide ways to help the person requiring support understand information, analyse information, and explore the strengths and weaknesses of any decisions and the options available.

- Be aware of their unequal relationship with the person they support and suspend their own judgments to ensure a person has their will and preferences acted upon, rather than acting on their best interest.

- Ensure the decision-making process includes communication of the process and decision to people who need to know.

The informal supporter must be able to access:

- Information and resources that meet their needs and are about the specific decision-making context.

- Accessible advice, resources and tools to share with the person requiring support.

5.5.2 Anticipated outcomes

- Increased understanding of supported decision-making and how to facilitate the process.

- Person with disability understands the pathway to access decision-making support.

- Person with disability builds confidence and capacity in decision-making, and the ability to inform others of their confidence about decisions. They feel safe, respected and listened to.

- Person with disability and supporters reflect on the decision-making process and recognise the decision.

5.6   Person making decisions

5.6.1 Steps to support decision-making

- Identify facilitators and barriers to supported decision-making, including:

    o   supporters (informal or paid)
    o   communication needs
    o   accessible resources
    o   cultural needs
    o   social and location context
    o   individual needs.

- Identify potential supporters, specifically established trusted relationships, to ensure ongoing and consistent support. This may include:

    o   family and friends
    o   peers
    o   other supports, including professionals.

- Identify the supporter's role in supported decision-making, for example, individual, group, specific types of decision.

- Ensure the supported person has support to understand information, analyse information, and explore the strengths and weaknesses of any decisions and the options available.

- Ensure the decision-making process includes communication of the process and decision to people who need to know.

5.6.2 Anticipated outcomes

- Increased understanding of supported decision-making and how to be supported through the process.

- Person understands the pathways to access decision-making support suitable to their needs and preferences.

- Person supported to make decisions suited to their needs and wants preferences.

- The person's support is transformative rather than transactional, allowing the person to build confidence and capacity in decision-making, and the ability to inform others of their confidence about decisions.

- The person feels safe, respected and listened to.

- Person and supporters reflect on the decision-making process and decisions are recognised.

6 How to operationalise the Principles and Guide

Operationalising the *Principles and Guide* means understanding supported decision-making as a process, not an outcome. Operationalising means identifying and deconstructing the process by which a decision or outcome is arrived at, to its constituent elements, in a way that those elements can be observed empirically, evaluated, and compared. The operationalisation of supported decision-making will need to be tailored to individual agencies based on the operational context and systems they operate in.

Steps towards operationalising supported decision-making include developing the empirical evidence base around what 'works' in different contexts, changing the social and institutional culture to one where the assumption is that all persons always have capacity, and delivering effective support for people who require decision-making support. Additional references and resources are presented in Appendix B.

The *Principles and Guide* recognise that individual need for support varies, and the level of support is proportional to decisions being made. Support for decision-making needs to be proportional in terms of not only the decision being made but proportional in terms of the level of support that's required. There is not necessarily a clear continuum of decisions that move from informal to formal support, but there are likely to be some types of decisions that need to be formalised to demonstrate transparency and safeguard the individual.

Operationalisation is dependent on the system and should occur at a systems level, in accordance with the legal context and the resources available, for each organisation. The *Principles and Guide* can be translated across systems, services and individuals, which can each draw on the growing resources, in terms of operational guidelines and tools, that suit different needs. The *Principles and Guide* also identify expected outcomes; this can form the basis of measures of success, reporting and evaluation – leading to greater accountability of supported decision-making practice. The actions that any organisation or individual takes will be limited by the resources available to them.

6.1   Key steps to operationalisation

A collective understanding (across government, services, and society) of what supported decision-making is – and is not – provides the foundation of successful supported decision-making. The absence of a collective understanding of supported decision-making was identified throughout this study as a barrier to effective implementation. This collective understanding and commitment to supported decision-making across all Australian jurisdictions – in both legal and non-legal frameworks – is critical.

Operationalisation should consider the process, not just outcomes from, supported decision-making. This will provide a measure of accountability and certainty – identifying the process behind a decision shows that a decision *was* arrived at by the person requiring decision-making support, and that it reflects their 'will and preferences' for example.

A broad way of beginning the process of operationalising is to consider the following 'core elements' of support *for* decision-making:

1. A question/issue is presented to a person with additional contextual information provided as required and alternatives.

2. The person requiring decision-making support consults with their preferred supporter/s.

3. The supporter must at all times seek to give effect to the 'will, preferences, and rights' of the person requiring decision-making support.

4. The person requiring decision-making support decides.

5. The decision is documented, acted upon, and is legally enforceable.

Recognising the complexities of the Commonwealth and the independence of states and territories, in line with the 2014 ALRC recommendations, this current study highlights the need to introduce specific 'will, preferences, and rights' language into legislation. Where possible, the concept of 'dignity of risk' should be explicitly stated in legislation and policy – '[a] person is not to be treated as unable to make a decision merely because he [or she or they] makes an unwise decision'.

6.2   Further research

Additional research required to support the operationalisation of supported decision-making include:

- Examining how supported decision-making may work in different domains outside of the traditional and obviously relevant domains such as guardianship, mental health, health, and aged-care. This includes domains such as justice, and children and young people.

- Developing an understanding of requirements for particular demographics, and individual factors including socio, economic and cultural factors of persons who require support for decision-making and their supporters. Understanding how or if culture or ethnicity may impact on how an informal support network may give effect to a person's will, preferences and rights.

- Developing a typology of decisions requiring support. This may range from day-to-day decisions to decisions relating to significant life decisions, whether that be relating to relationships, family, accommodation, health and finance. This will allow for better evaluation of the effectiveness of supports and will better allow tracking of whether a person requiring support develops decision-making skills over time.

- Developing a shared understanding as to what safeguards can be put in place for both informal and formal supported decision-making. Safeguards must not detract from people being able to access support for decision-making and establish relationships and networks to support this process.

- Identifying areas in policy and legislation where the 'will, preferences, and rights' concept needs to be introduced. This would provide consistency across all domains and systems.

- Developing standardised cross agency systems of accountability, with an emphasis on 'active reporting' – reporting on actions rather than events. Systems of accountability

should be co-designed with people who access decision-making support to develop formative and summative approaches that can be used across formal or informal support networks.

- Developing further resources to support particular demographics, including young people transitioning from best interest to will and preference, women, people in regional and remote areas, people from different cultures, Aboriginal and Torres Strait Islander peoples, and people with specific support needs.

Appendix A   Background to supported decision-making

In 2008 Australia ratified the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD).[3] The CRPD does not grant extra human rights - rather it applies human rights to the particular circumstances of people with disability. It is a response to the marginalisation, segregation and the unique challenges to personhood experienced by people with disability (Kayess & French 2008). Self-determination exemplified by the motto of the disability rights movement - 'Nothing About Us, Without Us' – is a critical principle that has shaped, and continues to shape, the struggle for the recognition of the personhood of all people with disability. The motto had a clear influence on the negotiations surrounding the CRPD, and its final form (Kayess & Sands 2020).

In addition, the drafting of the CRPD was given further guidance by the 'social model' of disability in which disability is viewed as a 'socially produced injustice' and not located within an individual (Lawson & Beckett 2021; Kayess & French 2008). The CRPD recognises that:

> [D]isability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (United Nations 2006, Preamble)

While the social model remains relevant, since the adoption of the CRPD in 2006 it is the 'human rights model of disability' that been at the forefront of the Committee on the Rights of Persons with Disabilities (Committee) on-going review of States implementation of the CRPD (Lawson & Beckett, 2021). The human rights model views people with disability as having equal worth, value and dignity as all human beings. It does not require a medical diagnosis. In their hugely influential 2002 work Quinn and Degner (2002) explained the human rights model thus (emphasis added):

> Human dignity is the anchor norm of human rights. Each individual is deemed to be of inestimable value and nobody is insignificant. People are to be valued not just because they are economically or otherwise useful but because of their inherent self-worth...The human rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It *places the individual center stage in all decisions affecting him/her* and*,* most importantly, locates the main "problem" outside the person and in society.

In this context, article 12 of the CRPD is arguably the most important to realising the principle of 'Nothing About Us, Without Us'. Article 12 affirms that all persons with disability have the right to equal recognition before the law. It recognises that a person with disability has a right to full recognition of their personhood (UN 2006 article 12(1)), and that they can 'enjoy legal capacity on an equal basis with others in all aspects of life' (UN 2006 article 12(2)). The obligation is placed firmly on States Parties to 'take appropriate measures to provide access by persons with

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[3] United Nations (2006). Convention on the Rights of Persons with Disabilities (entered into force in Australia 3 May 2008). The United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol on 13 December 2006.

disabilities to the *support they may require in exercising their legal capacity*' (UN 2006 article 12(5)) (emphasis added).

In introducing a 'supported decision-making' model that upheld the human dignity and autonomy of those requiring decision-making support, the CRPD completely rejected the continued use of prevailing 'substituted decision-making' schemes (such as Guardianship) as being incompatible with human rights principles. This is because substitute decision-making models irrevocably strip away recognition of a person's legal personhood, and denies that person's legal capacity, both in the sense of that person's legal standing (the ability to hold rights) and the exercise of legal agency (the ability to exercise rights) (ALRC 2014 [2.38]). The Committee have continued to state that jurisdictions that maintain substitute decision-making schemes are not compliant with the CRPD, regardless of Reservations made by them (United Nations 2014).

Safeguards

In rejecting substituted decision-making, and placing an obligation on States to establish and embed a new 'supported' decision-making paradigm the CRPD recognises there should be safeguards to protect from abuse. Article 12(4) CRPD states:

> States Parties shall ensure 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.

The Committee expanded upon this stating that (United Nations 2014 [21]):

> Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best interests" determinations. This respects the rights, will and preferences of the individual, in accordance with article 12, paragraph 4. The "best interests" principle is not a safeguard which complies with article 12 in relation to adults. The "will and preferences" paradigm must replace the "best interests" paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.

It is critical to note that 'will and preferences' replacing 'best interests' is the key safeguard factor underpinning supported decision-making generally. Thus, a minimal 'best practice' appropriate safeguard framework for *supported decision-making* based upon the CRPD and the General Comment No.1 should be one where decisions can be shown

- To give effect to the supported persons 'will and preferences'

- To be free of any conflict of interest

- To be free of any undue influence

- Where, after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best interests" determination.

- To be proportional to the persons circumstances, applied for shortest time and subject to review (in the case of best interpretation of will and preference).

Australian National Decision-Making Principles

In 2014 the Australian Law Reform Commission (ALRC) released its *Equality, Capacity and Disability in Commonwealth Laws* report. The report heralded an important step forward in the practical implementation of supported decision-making in Australia, and Australia's compliance with the CRPD generally and article 12 specifically. The ALRC recommended shifting from 'substituted' decision-making processes and there reliance on a 'best interests' test for capacity, to supported decision-making with its emphasis on giving effect to the 'will and preferences' of a person requiring decision-making support (ALRC 2014 [2.51]). 'Will' broadly refers to a person's more long-term aspirations and goals. 'Preferences' relates generally to more immediate matters, and are potentially quite variable and context dependent.

The ALRC developed four National Decision-making Principles to give guidance to government and others in the development of supported decision-making responses and schemes.

> **ALRC National Decision-Making Principles**
>
> Principle 1: Every adult has the right to make decisions that affect their life and to have those decisions respected.
>
> Principle 2: Persons who may require support in decision-making must be provided with the support necessary for them to make, communicate and participate in decisions that affect their lives.
>
> Principle 3: The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
>
> Principle 4: Decisions, arrangements and interventions for persons who may require decision-making support must respect their human rights.

The ALRC further proposed a Commonwealth decision-making model. Amongst other things, this model conceives of decision-making as being on a continuum, from supported decision-making at one end to 'fully' supported decision-making through a 'representative' at the other. As the ALRC state

> Article 12 of the CRPD and National Decision-Making Principle 2 contain the key idea of decision-making support. The central idea underlying the Commonwealth decision-making model is, therefore, that all adults, except in very limited circumstances, have some level of decision-making ability and should be entitled to make decisions expressing their will and preferences, but may require varying levels of support to do so (ALRC 2014 [4.8]).
>
> Rather than starting by questioning whether a person has the capacity to make decisions— reflecting a binary view of capacity and decision-making —the preferable approach is to ask

what level of support, or what mechanisms are necessary, to support people to express their will and preferences. This recognises that the ability of a person who may require decision-making support 'to exercise legal agency is dependent on the integrity, quality and appropriateness of support available' (ALRC 2014 [4.9]).

Principle three of the National Decision-making Principles reflects the critical concept of 'rights, will and preferences' that is outlined in CRPD article 12(3). Principle three and the application of will and preferences is given further clarity by the ALRC through the 'Will, preferences and rights guidelines', particularly in relation to contexts where a formal 'representative' has been appointed.

Will, Preferences and Rights Guidelines

Proposal 3–6 Will, Preferences and Rights Guidelines

(a) Threshold: The appointment of a representative decision-maker should be a last resort and not as a substitute for appropriate support.

(b) Appointment: The appointment of a representative decision-maker should be limited in scope, be proportionate, and apply for the minimum time.

(c) **Supporting decision-making:**

(i) a person's will and preferences, so far as they can be determined, must be given effect;

(ii) where the person's will and preferences are not known, the representative must give effect to what the person would likely want, based on all the information available, including communicating with supporters; and

(iii) if it is not possible to determine what the person would likely want, the representative must act to promote and safeguard the person's human rights and act in the way least restrictive of those rights.

The ALRC was cognisant of the need for safeguards for people who require decision-making support and identified some key safeguards as:

- outlining the duties of a supporter

- enabling a person who requires decision-making support to revoke any supporter relationships

- the ability to appoint more than one supporter

- engaging in capacity building through guidance and training for people who require decision-making support, for supporters, and for Government departments and agencies.

Challenges

The Committee has acknowledged the risk of undue influence being placed upon a person requiring decision-making support by another (United Nations 2014, [22]). They stated that:

> All people risk being subject to "undue influence", yet this may be exacerbated for those who rely on the support of others to make decisions. Undue influence is characterized as occurring, where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation. Safeguards for the exercise of legal capacity must include protection against undue influence; however, the protection must respect the rights, will and preferences of the person, including the right to take risks and make mistakes.

Concerns continue to be raised about the potential for people who require decision-making support to have their will and preferences ignored or otherwise have undue influence exerted upon them through an informal network/supporter (ALRC 2014 [4.88], Bigby & Douglas 2021, Bigby et al 2021, Carney 2017). Further, it has been suggested that in the context of informal support arrangements, safeguards are, in practice, potentially non-existent, and that safeguards described under the CRPD are unclear (Carney et al 2021).

There is some evidence that despite the growing awareness of supported decision-making, and a number of recent legislative reviews of Guardianship Schemes, for example in NSW and Victoria, there has been an increasing amount of people placed under guardianship like arrangements since the introduction of the NDIS, where the rate had been falling or steady previously (Bigby et al 2021).

The adoption by governments of supported decision-making frameworks in both legislation and policy remains inconsistent and uneven amongst all Australian (and international) jurisdictions. While not relevant for many day-to-day contexts, legal recognition of the supported decision-making process, the legal validity of a decision made by a person who requires decision-making support (such as when entering a contract), and the legal status of people who provide support to a person requiring decision-making support through an informal arrangement remains unclear (Then et al 2018). How to best recognise the position of supporters in law remains a key question (ALRC 2014 [3.20]).

Substituted decision-making in various guises remains a feature of the decision-making landscape, both in Australia and Internationally, with no jurisdiction technically fully complaint with the CRPD (Alston 2017, Arstein-Kerslake et al 2017). The Committee on the Rights of Persons with Disabilities (the Committee) has stated clearly that all practices that in purpose or effect 'violate'

article 12 of the CRPD, including substitute decision-making schemes, must be 'abolished' so that full legal capacity can be restored to persons with disabilities (United Nations 2014).

Evaluation of the effectiveness of supported decision-making policies and procedures, and supported decision-making capacity building programs (whether aimed at supporters, persons who require decision-making support or professional staff) continues to be of mixed quality in Australia and internationally. There is a gap in our knowledge in Australia about how to provide support for decision-making, and what information, capacity building, and infrastructure are required for informal and formal supports in different contexts (Bigby, Whiteside & Douglas 2019)). While it should be noted that the empirical evidence base as to 'best practice' is pleasingly improving in Australia, there remains little empirical evidence about the 'fidelity to purpose' of supported decision-making and how it is able to deliver on the promises of both empowering persons requiring support and safeguarding them from abuse (Bigby & Douglas 2021).

Opportunity

Recent empirical studies have shown that supported decision-making capacity building programs targeted at supporters and front-line staff at agencies, can measurably improve their reflective ability to identify will and preferences and give effect to it (Douglas et al 2020).

Appendix B References and additional resources

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