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# Good Practice in Supported Decision-making for People with Disability

A desktop review of the evidence for best practice principles for supported decision-making

Prepared for: Australian Government, Department of Social Services

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## **Acknowledgements**

The research team acknowledges the input and support of the DSS project team. The research team would also like to extend our gratitude to the individuals and organisations who participated in this study.

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The Social Policy Research Centre is based in the Faculty of Arts, Design and Architecture at UNSW Sydney. This report is an output of the 'Good Practice in Supported Decision-making for People with Disability' research project, funded by the Australian Government, Department of Social Services.

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# Abbreviations

ABS	Australian Bureau of Statistics
ALRC	Australian Law Reform Commission
Committee	The Committee of the Rights of Persons with Disabilities
CRPD	United Nations <i>Convention on the Rights of Persons with Disability</i>
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

# 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 Disability* (CRPD), which have practical application and work across systems such as justice, mental health, health and child protection. The research team was asked to undertake a desktop review of the relevant literature to inform the study. This report presents the findings of the desktop review.

## 1.1 Overview and scope

As of 2019 there were approximately 4.4 million Australians with disability.<sup>1</sup> The ABS has estimated that of that 4.4 million, almost 3.9 million people had some level of limitation with their core activities of communication, mobility, or self-care, and/or a schooling or employment restriction.<sup>2</sup> The ABS identified that regarding the core limitations, as a proportion of the Australian population, 3.2% of people had a profound limitation; 2.6% had a severe limitation; 2.4% had a moderate limitation; 6.1% had a mild limitation; and 1.4% had a schooling or employment restriction only. The ABS estimates that at least 39.7% of people with disability living in a household need help with at least one cognitive or emotional activity, and that at least 12.2% require assistance in the core activity of communication directly.<sup>3</sup>

People with disability continue to encounter pervasive discrimination across all life domains in Australia (Kayess & Sands, 2020). People with disability receive lower incomes, have poorer and less stable housing, face increased risk of violence, abuse and neglect, have reduced educational and employment opportunities, and have reduced access to health services and worse health outcomes overall.<sup>4</sup>

Persons with a cognitive disability are particularly vulnerable to abuse and marginalisation. This is due to a lack of infrastructure and support measures to support people with disability which can limit their ability to be understood and to understand others. This may also hinder their ability to access information and communicate their will and preference and to exercise their rights. The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD), and particularly

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<sup>1</sup> ABS 2019, Disability, Ageing and Carers Australia <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release> ; AIHW 2020, People with Disability in Australia 2020 <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/summary>

<sup>2</sup> Note that there are differences in the definition and identification of disability amongst a number of different collectors of data. The AIHW (2020, 9) notes that the Australian Bureau of Statistics' (ABS) Survey of Disability, Ageing and Carers (SDAC) uses a comprehensive set of questions to determine disability and is considered the gold standard of disability identification in Australia.

<sup>3</sup> ABS 2019, Disability, Ageing and Carers Australia <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release> ; AIHW 2020, People with Disability in Australia 2020 p. 26 <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/summary>

<sup>4</sup> ABS 2019, Disability, Ageing and Carers Australia <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release> ; AIHW 2020, People with Disability in Australia 2020 <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/summary>

article 12, makes clear that the assumption always remains that a person is capable of exercising autonomy and retains full legal capacity (United Nations, 2006; 2014). A critical element of the CRPD is that it directly places an *obligation* on states to provide all the necessary support/s to people with disability to ensure their will, preferences and rights are recorded and respected. The concern of the supported decision-making paradigm ushered in by the CRPD is in preserving and supporting the expression of the legal capacity of persons with disability. Supported decision-making is contrasted with substitute decision-making schemes, such as those found in traditional guardianship arrangements, where autonomy is removed from a person (United Nations, 2014).

This desktop review is examining the literature on best practice or good practice in the design and implementation of formalised or informal supported decision-making initiatives. It identifies some broad, consistent and general best practice principles that can be used and adapted across various supported decision-making approaches and considered in policy across all domains. This desktop review also identifies broad recommendations for further research, consistent with advancing understanding of what best practice in supported decision-making *can* look like.

## 1.2 Background

The failure to understand and respect a person's will, preferences and rights represents a significant attack on an individual's personhood and right to self-determination (Wiesel et al., 2020). A human rights model of disability as set out by the CRPD asks us to eschew any assumptions that a person is lacking in legal capacity because they may have a cognitive disability. Rather, as the Australian Law Reform Commission (ALRC) made clear in its landmark 2014 report, the contemporary human rights interpretive model of disability demand attention be focused on what support/s a person may require in exercising their legal agency (ALRC, 2014, 47).

This fight for recognition of voice is exemplified in the ground-breaking 1983 Canadian case of *Clark v Clark*<sup>5</sup> in which Justin Clark, who was born with significant cerebral palsy sued his parents for the right to make his own decisions. Justin communicated via a Bliss board (allows users to communicate by pointing at symbols). Justin was able to give his powerful testimony in court using this device, with a person assisting in translation. In giving judgment Justice Matheson ended by stating:

We have, all of us, recognised a gentle, trusting, believing spirit and very much a thinking human being who has his unique part in our compassionate interdependent society.

And so, in the spirit of that liberty which Learned Hand tells seeks to understand the minds of other men, and remembers that not even a sparrow falls to earth unheeded, I find and I declare Matthew Justin Clark to be mentally competent.

Justin Clark's case was a huge influence on the burgeoning disability self-determination movement and its motto of 'Nothing about us, without us', and was by all accounts, a considerable influence on debates surrounding aspects of the development of the CRPD.<sup>6</sup>

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<sup>5</sup> (1983), 40 O.R. (2d) 383.

<sup>6</sup> CBC, How Justin Clark's fight for independence transformed disability rights in Canada (November 25, 2018) <https://www.cbc.ca/radio/sunday/november-25-2018-the-sunday-edition-with-michael-enright-1.4911588/how-justin-clark->

The CRPD was adopted in 2006 and came into force in 2008. It was ratified by Australia in 2008.<sup>7</sup> As of March 2021, 182 countries have ratified the convention. 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). The drafting of the CRPD was given initial guidance by the social model of disability in which disability is viewed as a 'socially produced injustice' and not located at an individual (Lawson & Beckett 2021; Kayess & French 2008). This social model is recognised and expressed in the CRPD as follows:

[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 the emergent human rights model of disability that been at the forefront of the on-going review of States implementation of the CRPD by the Committee on the Rights of Persons with Disabilities (Committee) (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. The critical point is that *impairment of any kind is not a basis for any denial of human rights*. 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.

The human rights model and context is the framework adopted by the authors of this review. The authors of this report acknowledge that language used in some instances in the literature cited may not correspond entirely with contemporary usage and understanding. Where possible this has been corrected and otherwise provides context. Note that understanding and use of language are constantly evolving in this space.

The purpose of the CRPD is articulated in article 1:

### **Article 1 – Purpose**

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[s-fight-for-independence-transformed-disability-rights-in-canada-1.4911590?x-eu-country=false](#) . In Australia note the influential work on Facilitated Communication by Anne McDonald and Rosemary Crossley from 1977.

<sup>7</sup> The National Disability Strategy is the main mechanism for the implementation of the UN CRPD in Australia. The CRPD principles are also reflected in the *Australian Human Rights Commission Act 1986* (Cth) and in the mechanisms for the delivery of services to people with disability such as the NDIA and NDIS) (see e.g. AIHW 2020). For example, *National Disability Insurance Scheme Act 2013* (NDIS Act) section 3(1)(a) states that the Objects of the NDIS Act are to 'in conjunction with other laws, give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006 ([2008] ATS 12)'. But note that in Australia it is individual states who are responsible for Guardianship and Mental Health laws and thus have the largest impact on directly removing substitute decision-making regimes.

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

A key element of the CRPD is respect for human dignity and worth, and central to this is autonomy. Article 12 affirms that all persons with disability have the right to equal recognition before the law, and means that all persons, regardless of real or perceived impairment always retain full legal capacity and autonomy.

Critically, article 12 is seen to be a rejection of *substituted decision-making* schemes such as those underpinning traditional guardianship law that can undermine personhood and autonomy, in favour of the adoption of *supported decision-making* processes which always recognise and respect a person's legal capacity.

### 1.3 Method

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 Commonwealth Department of Social Services on previous iterations, and through feedback received through the separate stakeholder consultation process.

The general question guiding this 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 this document. 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.

## 1.4 Limitations and context of the current desktop review

A desktop review was selected as being the most appropriate form of analysis due to the short timeframe of this project. The emphasis of the desktop review was on generating a broad reference list and a quick and broad general understanding of the literature that can be applied immediately to inform subsequent project phases and provide some clarity and guidance as to future direction. Being a desktop review, it can also be considered a working document that can be added to and updated as required in the future. It is not as deep in analysis as a literature review.

To maintain a manageable scope, the review is focused largely on adults with a cognitive disability who may require decision-making support. Applying CRPD article 12 to the day-to-day experience of children and young people with disability generally, and the context of child protection specifically is complex. In Australia, children and young people operate at law within a recognised best interests framework (including within the family law sphere) that reflects the approach established by article 3 of the United Nations *Convention on the Rights of the Child* (CROC) (entered into force on 2 September 1990). Article 3(1) states that:

(1) In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

In respect of the child protection or justice, the manner in which a child or young person's voice is recognised in legal interfaces is complex. Processes to consider the voice of a young person in a final decision are outlined in the relevant child protection legislation in each state/territory, and is designed to comply with CROC. For example, in NSW, the *Childrens and Young Persons (Care and Protection) Act 1998*, (NSW Care Act) section 9(2)(a) states:

(2) Subject to subsection (1), the other principles to be applied in the administration of this Act are as follows:

(a) Wherever a child or young person is able to form his or her own views on a matter concerning his or her safety, welfare and well-being, he or she must be given an opportunity to express those views freely and those views are to be given due weight in accordance with the developmental capacity of the child or young person and the circumstances.

Section 10 of the *NSW Care Act* develops this further in outlining the 'Principle of Participation' which states that

(1) To ensure that a child or young person is able to participate in decisions made under or pursuant to this Act that have a significant impact on his or her life, the Secretary is responsible for providing the child or young person with the following:

- (a) adequate information, in a manner and language that he or she can understand, concerning the decisions to be made, the reasons for the Department's intervention, the ways in which the child or young person can participate in decision-making and any relevant complaint mechanisms,
- (b) the opportunity to express his or her views freely, according to his or her abilities,
- (c) any assistance that is necessary for the child or young person to express those views,
- (d) information as to how his or her views will be recorded and taken into account,
- (e) information about the outcome of any decision concerning the child or young person and a full explanation of the reasons for the decision,
- (f) an opportunity to respond to a decision made under this Act concerning the child or young person.

(2) In the application of this principle, due regard must be had to the age and developmental capacity of the child or young person.

In all Australian jurisdictions there exists specialist children's lawyers who work to assist young people to navigate relevant legal proceedings. But note in both examples above – age and developmental ability are still considered. And further note that final *decisions* as to a child's welfare are invariably based upon what a court considers to be in a child's best interests. Because of this, it is difficult to consider how supported decision-making is of specific relevance outside of the adult sphere – while children are provided with support to understand proceeding's, final decisions are *not* made by them. Even in situations where a child may actually come to a certain decision on a topic and express that view (for example, as to which parent they prefer to live with) there is no guarantee a court will give effect to it. The authors of this report are not arguing that children should not participate in proceedings. Just that supported decision-making as properly understood, *may* not be of any more benefit to a child or young person over and above what is already available via CROC and other relevant legislative supports in existence.

This is similar to interventions in the adult criminal justice sphere that seek to provide an accused person with support to understand proceedings for example. Simply providing support to a person for them to understand proceedings is not by default supported decision-making and it is challenging to consider how supported decision-making may provide more benefit and safeguards to adults with cognitive disability who interact with the criminal justice sphere above and beyond what is currently available via legislation and common law for example. This should not detract from the inherent good of ensuring supports generally should be available for a person to help them understand the nature of any criminal or civil proceedings they are involved in so they may fully participate.

In the context of applying supported decision-making to domains outside of guardianship, the interfaces are complex and worthy of further independent review and analysis.

For example, the authors of this review identify the need for further research examining the recognition of the evolving capacities of children and the transition of a child with cognitive

disability from a best interests framework as under CROC to an adult will, preferences and rights framework (under the CRPD). This should explore how a child or young person can be supported to better navigate will and preferences, considering they have had little exposure to making decisions as a child, and developing an awareness of what will and preferences entails. In reflecting on their work with transition-age youth, Glen (2017, 517) observes that:

[A]lthough decision-making may appear to evolve 'naturally' for neuro-typical children, it is a skill that must be explicitly and systematically taught to those with intellectual and developmental disabilities, beginning not at transition, but at the start of the educational journey, as early as pre-kindergarten.

## 1.5 Terminology

The term cognitive disability, following Wiesel et al. (2020) and Douglas et al. (2015), means both people with intellectual disability that they were born with, and people with an acquired brain injury (ABI). In both cases, cognitive disability is associated with requiring support to understand or communicate new or complex information and to learn and apply new skills for example (Douglas & Bigby, 2020; Wiesel et al. 2020).

The ALRC (2014) has noted the confusion over terminology that surrounds article 12, and supported decision-making, such as the word capacity with some terms being used interchangeably. They note that capacity is regularly confused with legal capacity, and legal capacity is regularly conflated with mental capacity. The ALRC uses the word ability in the sense 'that the focus should be on assessing how the individual can be supported to exercise their ability' (2014, 47).

It has been noted across the literature that the terms choice and decision are usually not clearly defined or distinguished from each other (Bigby & Douglas, 2020a; Bigby et al., 2017).

Then and Carney (2018) note that the term supported decision-making has no fixed definition (it is not defined in the CRPD) but is commonly used in relation to both the *practical process* and *legal recognition* of the practice of supported decision-making. Expanding on this, Wiesel et al. (2020) and Bigby and Douglas (n.d.) distinguish between:

- 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.

The authors of this review agree this is a useful distinction to bear in mind, though do still refer to supported decision-making in a general sense depending on context.

## 1.6 Gaps in the literature

A theme highlighted across multiple existing systematic reviews of the literature on supported decision-making since 2000 is the significant lack of empirical research from Australia and

internationally demonstrating what best practice in supported decision-making looks like, or how it works (Alston 2017; Bigby & Douglas, n.d.; Bigby et al., 2015; Carney 2015a, 2015b; Douglas et al., 2015; Gooding, 2015; Harding & Tasciglu, 2018; Mirfin-Veitch, 2016; Then et al., 2018). Where specific evaluations of programs do exist in Australia, Bigby et al. (2017) argues that they were 'primarily descriptive, did not use representative samples or validated tools and did not compare pre- and post-outcomes', and that these limitations mean that only tentative conclusions can be drawn about the effectiveness of the programs and the design features that influenced their outcomes.

Similarly, Carney (2015a, 41) argues that the existing Australian pilot studies of different models of support he examined are 'few in number, small in scale and unable to afford a rigorous evaluative design'. Moreover, there does not appear to be agreement or consistency as to how programs should be designed or evaluated (Alston, 2017).

Douglas et al. (2015) note that serious doubts have been raised by commentators about the capacity of such schemes to deliver their intended benefits or cater for all groups of people with cognitive disabilities, regardless of cultural background. This lack of evidence as to efficacy of supported decision-making exists across both formal schemes that may have a legislative basis or are otherwise recognised in law, and more informal arrangements (Carney, 2015a).

The historical lack of a rigorous standardised qualitative evaluation framework that would provide a strong empirical evidence basis to inform legislative amendment, structure policy development, and guide program implementation has led to some calling for restraint or caution in the reform process, lest legislators engage in overly 'experimental law making' (Carney, 2015a, 2015b). However, just how much caution is warranted in practice by this apparent lack of empirical evidence has been questioned (Alston, 2017; Gooding, 2015). For example, Gooding (2015) notes (surprisingly) that there is also little evaluative empirical literature on existing guardianship regimes generally; the conceptual basis for the best interests standard; or the efficacy of other substitute decision-making mechanisms in law. Similarly, internationally, Series (2015) observed that the literature on the experiences of people who are subject to guardianship and mental capacity laws is very sparse.

Finally, Alston (2017) argues that calls for evidence regarding support to exercise legal capacity must be weighed against the qualitative criteria for justifying reform of existing substituted decision-making law and policy frameworks. In bringing about the CRPD, the international community has agreed that supported decision-making is a *good* thing, and something that should be pursued because it is seen as having *inherently* good characteristics. The question is not whether supported decision-making is a worthy goal to work towards; the question becomes more of 'how to best implement supported decision-making so that it is aligned with the expressed values in the CRPD'?

## 1.7 La Trobe Decision-making Framework

Notwithstanding the general validity of the comments above, there has been an improvement in the empirical evidence-base for supported decision-making since 2015. Systematic research has been done on supported decision-making and health, mental health and consumer transaction at the Melbourne Social Equity Institute and the Melbourne Disability Institute for example.

A key driver of this improvement in the evidence-base in Australia (and which has been picked up on globally such as in Canadian jurisdictions) has been the work of the **La Trobe University Support for Decision-making project/s**, which has engaged in the delivery, and evaluation of several programs aimed at capacity building in supporters and persons requiring decision-making support.<sup>8</sup>

Led by Professors Christine Bigby<sup>9</sup> and Jacinta Douglas, from the **Living with Disability Research Centre** at La Trobe University, in addition to high quality evaluative reports, and peer reviewed publication, a key output of the projects to date has been the development of an *empirically based* 'Decision-Making Practice Framework' and associated resources to provide supporters with the tools and knowledge to best recognise and give effect to a persons will, preferences and rights.<sup>10</sup>

The quality of the associated resources is high. This practice framework is now being adapted by government agencies (for example, most recently, the Queensland Public Trustee) to guide their implementation of supported decision-making initiatives.<sup>11</sup> The La Trobe team is undertaking a project regarding this adaptation and implementation led by Professors Bigby and Douglas: 'Support for decision-making: Adapting the La Trobe Support for Decision-making Practice Framework for the Queensland Public Trustee'.

The La Trobe Framework (replicated in Figure 1 below) sets out seven components or steps that all decision support practice involves, the three principles that should inform support, and the broad strategies used across steps that are tailored to the individual and step.

The Framework is intended as a guide for supporters to decision support practice aligned with the intent of the UNCRPD, i.e. practice that prioritises participation in decision-making by a person with intellectual disabilities and puts respect for their will, rights and preferences at its centre. It also provides a set of criteria to serve as a means of reflective accountability for supporters. The Framework is applicable to paid [formal] or informal supporters of people with either intellectual disabilities or acquired brain injury and can be adapted to different policy and service contexts. For example, to date it has been used by family members, direct support workers in a variety of settings, support coordinators in a statutory insurance scheme for road traffic accident victims, an advocacy organisation to pilot a supported decision-making program utilising paid supporters for people without informal support, and an organisation responsible for substitute financial decision-making support of people with cognitive disabilities. Training in the Framework and follow up mentoring to help supporters apply it to their own context have been shown to positively impact on the practice of supporters, by increasing their self-awareness and strategies that further participation. (Bigby & Douglas n.d., 12)

The seven steps apply regardless of context or nature of the decision, i.e. can be applied in proportion to the decision being made. The three principles in the centre underpin the practice of all decision making support.

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<sup>8</sup> <https://www.latrobe.edu.au/lids/research/building-the-evidence-base-for-participation>

<sup>9</sup> <https://www.latrobe.edu.au/lids>

<sup>10</sup> <https://www.supportforddecisionmakingresource.com.au/>

Figure 1 La Trobe Framework



## 2 Recommendations for further research

The following recommendations are based on a review of current literature as well as feedback generated from consultations held with stakeholders as part of this project – Good Practice in Supported Decision Making for People with Disability. While they can be seen as filling in gaps, the contributions from the stakeholder consultation (both face-to face and written submissions) help to give the recommendations an operationalising element to supported decision-making by focusing on specific background details to the larger observable processes. These recommendations seek to progress understanding and practice of supported decision-making in a tangible way from the current state.

These recommendations can be considered to contain elements of both support *for* decision-making (practice undertaken by supporters when assisting a decision-maker) and *support* for decision-making (agency, legal and policy structures underpinning supported decision-making) – both abbreviated to SDM.

1. Clarity around what SDM is (and is not). Development of a shared institutional, systems, and formal and informal network understanding of SDM.
2. Given a clear understanding of what SDM is, examine how SDM may work (if at all) in different domains outside of the traditional and relevant domains like Guardianship, Mental Health, Health, Justice, and Child Protection.
3. Develop a deeper understanding of demographics, and individual factors including socio-cultural factors of persons who require decision-making support and their supporters to better tailor services.
4. Understand how or if cultural, ethnicity or LGBTIQ+ identity may influence how an informal support network may restrict the expression of the will, preferences, and rights of a person who requires decision-making support, and consider safeguards that are culturally safe.
5. Ascertain how many people currently require some degree of decision-making support, and the frequency of that requirement.
6. Development of a typology of distinct types of decisions. For example, decisions about day-to-day living such as meal preferences; social events; personal relationships; health; work and employment; legal decisions; and financial decisions. Note though, often big themes such as life domains or other ‘mega questions’ are currently used without ‘drilling down’ into the underlying process. Breaking down the diverse types of decisions into more specific elements will allow for better evaluation of the effectiveness of support relationships and will better allow us to track how a person requiring support can ‘improve’ capacity over time for example.
7. Given a shared understanding of what supported decision-making is, developing a shared understanding as to what safeguards can be put in place for both informal and formal supported decision-making frameworks across all their complexities and intersectionality.

8. Identify areas in policy and legislation where the will, preferences and rights concept can be introduced, even if independent of some formalised supported decision-making schemes. This is relevant for the process of incremental cultural change and policy consistency across all domains including health, mental health, children and young people, and justice, and jurisdictions.
9. Development and promotion of a standardised evaluative structure for SDM programs and arrangements including informal and formal arrangement and programs.
10. Place a significant emphasis on giving voice to the experience and the perspectives of people who receive decision-making-support as to what constitutes 'good practice' for them.
11. Develop standardised cross-agency and systems accountability or quality assurance mechanisms, with an emphasis on 'Active Reporting' – reporting on actions rather than events. Consider formative and summative approaches that can be used across formal or informal support networks.
12. Develop data capture tools to collect cross-agency data to capture/measure 'proportionality' across the contexts (need to be noticeably clear and define what is meant by proportionality).
13. Where not explicitly stated, all recommendations should be considered in the context of the specific needs of Aboriginal and Torres Strait Islander communities, CALD communities, and persons identifying as LGBTIQ+. Further research needs to be urgently undertaken to better understand the specific needs of Aboriginal and Torres Strait Islander communities and CALD communities and how to best engage them in a manner that is culturally safe.



## 3 Article 12 of the CRPD

Article 12 of the CRPD provides for equal recognition before the law.

### Article 12 – Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. 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.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

This section of the desktop review explores article 12 in more detail, how it relates to supported decision-making and substituted decision-making, and how it may be operationalised.

### 3.1 Legal capacity at international law

Article 12(1)(2) of the CRPD affirms that a person always holds legal capacity, and a person has a universal right to exercise legal capacity on an equal basis with another. A person never loses their legal personhood or legal identity. It is through article 12(3) that the specific mechanism is established: States parties must actively provide the resources or other measures to ensure that persons with disabilities are able to exercise their legal capacity, and measures relating to the exercise of legal capacity must ensure respect for the rights, will and preferences of the person (CRPD article 12(4)). Any impediment to the ability of a person to exercise one's legal capacity is a restriction to the equal enjoyment of a person's human rights and is unacceptable.

It is important to understand the way that legal capacity as it is used in the CRPD, has come to be seen. There is consensus (Callaghan, 2016) that it comprises two concepts that were 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 traditional general law conception of legal capacity is concerned solely with agency and the ability of a person to make a decision. In combining them, the current view is that 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 brings 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 (Callaghan, 2016).

## 3.2 Supported decision-making vs substitute decision-making

The Committee of the CRPD in the *General Comment 1* provides a definition of substituted decision-making:

Substitute decision-making regimes can take many different forms, including plenary guardianship, judicial interdiction and partial guardianship. However, these regimes have certain common characteristics: they can be defined as systems where (i) legal capacity is removed from a person, even if this is just in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will or (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective 'best interests' of the person concerned, as opposed to being based on the person's own will and preferences. (United Nations, 2014, [27])

Supported decision-making originated in Canada in the 1990s as a process to challenge and overcome the legal barriers that prevented people with cognitive disabilities from receiving individualised funding (Bigby et al., 2017). The critical characteristic of supported decision-making, when compared to substitute decision-making schemes, is that:

With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decision-maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when the person with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual. This distinguishes supported decision-making from substituted decision-making, such as advance directives and legal mentors/friends, where the guardian or tutor has court authorized power to make decisions on behalf of the individual without necessarily having to demonstrate that those decisions are in the individual's best interests or according to his/her wishes (United Nations, 2007, 89-90)

Thus, in contrast to substitute decision-making, supported decision-making usually involves the person retaining their legal powers of decision-making (Carney, 2013).

Browning et al. (2014, 34) provided an early framework to conceptualise, supported decision-making in three ways:

1. As 'a process of supporting a person with decision-making'

2. As 'a system that affords legal status' and
3. As 'a means of bringing a person's will and preferences to the centre of any substituted decision-making process.'

Most recently, Bigby and Douglas (2020a) argue that supported decision-making can be considered as either practice (providing support to a person), or a legal or policy scheme. Carney (2015a, 2015b) suggests supported decision-making, like substitute decision-making, is directly relevant for four main groups of people who experience cognitive impairment:

1. People with intellectual disability
2. People with a mental illness (psychosocial disability)
3. People with an acquired brain injury, and
4. People living with dementia.

Browning et al. (2020; see also United Nations, 2014; Shogren et al., 2017) identify that supported decision-making has two main aims:

1. '[T]o enable people with cognitive disabilities to exercise their legal capacity', and
2. '[T]o determine their own lives'.

SDM can also be seen as a framework in which a person who requires decision-making support can access support from a third-party to assist them in making decisions that reflect their will and preferences, uphold their rights, and give full effect to the exercise and expression of their legal capacity and the promotion of self-determination (Arstein-Kerslake & Flynn, 2015; Browning et al., 2014; Kohn & Blumenthal, 2014; Werner & Chabany, 2015). For Carney (2017b) a distinguishing element of the supported decision-making paradigm is that it shifts the focus from the capacity of the person being assisted, to the adequacy of the supports available through the rejection of the idea of *incapacity*, the assertion of an 'entitlement to receive assistance', and an obligation on the state to provide that assistance (Carney, 2017b).

Supporters and other support mechanisms can assist in the provision of information germane to a decision, identify relevant considerations, increase understanding, and help to communicate decisions made (Mirfin-Veitch, 2016). Supported decision-making should not be considered a one size fits all approach. For support to be effective, in the sense that the supports do assist a person to have their will and preferences recorded and respected, the type of support provided must be based upon the supported persons individual needs (Pathare & Shields, 2012; United Nations, 2014).

The Committee in the *General Comment 1* (United Nations, 2014, [17]) notes that article 12 does not specify what form the support should take. They state that:

'Support' is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity

for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication. Support to persons with disabilities in the exercise of their legal capacity might include measures relating to universal design and accessibility — for example, requiring private and public actors, such as banks and financial institutions, to provide information in an understandable format or to provide professional sign language interpretation — in order to enable persons with disabilities to perform the legal acts required to open a bank account, conclude contracts or conduct other social transactions. Support can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences. For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others.

Some tension as to the proper interpretation of article 12 remains despite the Committee intending to clarify any ambiguity in its 2014 *General Comment 1* (United Nations, 2014). Watson (2017, 3) argues the key tension exists ‘around the relevance and application of article 12 for people whose intellectual disability is at the more severe end of the continuum’. Mirfin-Veitch (2016) further identifies that the tensions and debates include considerations about:

- How to theorise supported decision-making for individuals with severe cognitive impairment.
- How to determine when a person requires assistance with decision-making.
- How to identify and manage situations whereby a person’s will and preferences conflict.
- How to determine and how to respond when people and their supporters have conflicting will and preferences, and
- The nature and extent of safeguards required for people, and in some cases their supporters, in the Convention era.

Mirfin-Veitch (2016) observes that scholars do not agree on the extent to which disabled persons can be engaged with on a purely voluntary basis and whether substituted decision-making is a necessary last resort option, or whether it can be replaced in its entirety by *different forms* of supported decision-making (such as facilitated decision-making).

One side of the debate argues that there will always be cases where a person is too dangerous (of relevance particularly in the Justice sphere as well), lacks a sufficient understanding of the decision, or is completely unable to communicate their will and preference despite assistance being made available (see Gooding, 2015; Mirfin-Veitch, 2016). The ALRC (2014) has referred to these as ‘hard cases’. The existence of hard cases means that some form of substitute decision-making process (referred to by the ALRC as ‘representative decision-making’) must remain as a last resort (ALRC, 2014).

On the other side of the debate, it is argued that it is critical to optimise people’s true will and preferences as much as possible, and that violating the equal rights and dignity of people through proxy (substituted decision-making) is not permissible under any circumstances (see United Nations, 2007; 2014; Kohn & Blumenthal, 2014).

It is also argued from this body of literature (though not always convincingly), that people's will and preferences can always be ascertained, even if it means proceeding based on information known about them, which enables that person to exercise their agency through a third-party (see Arstein-Kerslake & Flynn, 2015; Devi, 2013; Flynn & Arstein-Kerslake, 2014; Mirfin-Veitch, 2016). It is also argued that disability-neutral options are available to states parties to protect disabled people and others from danger (see Mirfin-Veitch, 2016).

No state has fully given effect to article 12 in line with the interpretation of article 12 put forward by the Committee (Mirfin-Veitch, 2016). In most states there has been a legislative assumption that there will always be cases of persons for whom substitute decision-making must be undertaken (Mirfin-Veitch, 2016). Relatedly, Then et al. (2018) note that internationally there is no clear model of supported decision-making that has been advocated by law reform bodies.

While it is the case that currently no Australian or International jurisdiction is fully compliant with the CRPD and article 12 – because they retain elements of substituted decision-making in guardianship schemes for example – the CRPD and article 12 has served as a catalyst for more general reforms around legal capacity in all Australian and several international jurisdictions. States parties' efforts to harmonize domestic laws with the CRPD, including article 12, have primarily focused on reforming guardianship and mental health laws on one hand, and improving access of consumers to agencies and service providers on the other.

In 2017, the UN Special Rapporteur on the Rights of Persons with Disabilities relayed that law reform on the right to legal capacity had been either initiated or concluded in at least 32 countries since the entry into force of the Convention.<sup>12</sup> They stated that '[w]hile most of these laws and bills are not in full compliance with Article 12 of the Convention, they show that a growing number of States acknowledge that their legal systems and particularly their substitute decision-making regimes, fail to guarantee the rights of persons with disabilities'.<sup>13</sup>

### 3.3 Operationalising supported decision-making

Operationalising means the identification of specific indicators and components that can then be observed empirically and evaluate for efficacy (Arstein-Kerslake et al., 2017). Arstein-Kerslake et al. (2017) argues the operationalisation of supported decision-making is of critical importance to ensuring policy and practice are right. Further, Carney (2015b) argues that a problem with most current studies on best practice on supported decision-making is that they concentrate on assessing the more extensive forms of assistance, and neglect the more routine, day-to-day, or ordinary situations where support may be needed. It is the identification and categorisation of these routine situations that is the basis for operationalisation.

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<sup>12</sup> Catalina Devandas Aguilar, *Report of the Special Rapporteur on the Rights of Persons with Disabilities* (theme: legal capacity reform and supported decision-making) (12 December 2017), at para 38 online: United Nations Human Rights Office of the High Commissioner <<https://www.ohchr.org/Documents/Issues/Disability/A.HRC.37.56.docx>>

<sup>13</sup> Catalina Devandas Aguilar, *Report of the Special Rapporteur on the Rights of Persons with Disabilities* (theme: legal capacity reform and supported decision-making) (12 December 2017), at para 38 online: United Nations Human Rights Office of the High Commissioner <<https://www.ohchr.org/Documents/Issues/Disability/A.HRC.37.56.docx>>

Similarly, Bigby et al. (2015) argue that attention to the creation of appropriate legal structures, while important, has neglected the crucial issue of the actual practice of delivering support for decision-making across relevant contexts. This has contributed to a policy landscape in which '[t]here is little evidence on what works in terms of ensuring the will, preference and rights of people with cognitive disability are actually at the centre of decision-making' (Bigby et al., 2015, 6).

Despite this shift, there is a concern that, notwithstanding signatory nations' best intentions, there is an impending danger *that in the rush to operationalise supported decision-making* the objective of article 12 may be lost. Without close attention to the mechanics of how supported decision-making is implemented, there is a risk that it will become another tick box exercise, more to serve a bureaucratic purpose than to provide genuine choice and control for people with disability (Arstein-Kerslake et al., 2017).

In part, this caution about wholesale adoption of supported decision-making is warranted; international evidence of what types of assisted decision-making regime work is lacking, along with information about its possible differential appeal based on personal characteristics of people involved (e.g., a cultural preference for collaboration). As noted previously, Australian pilot studies of different models of assistance are 'few, small in scale, and unable to afford a rigorous evaluative design' (Carney, 2015a; Bigby et al., 2017). They also arguably concentrate on the more extensive forms of assistance required by people with more profound levels of cognitive impairment, to the neglect of the more routine day-to-day situations where assistance may be needed (Carney, 2015a), an understanding of which is recognised as critical for the process of operationalising supported decision-making.

Operationalising respect for will, preferences, and rights within supported decision-making schemes has been described as posing a wicked problem. Carney (2017b) argues the wicked problem lies in the inability to render concrete the safeguards called for by the CRPD to ensure that the 'will and preference' of the person being supported is being respected.

Supported decision-making is, or should be, an organic process, which needs to be engrained within the daily process of decision-making, as well as specific formal decisions. Stainton (2016) argues that this is the most critical aspect of supported decision-making for service and support providers, and critical to true personhood for those who rely on such services.

Providing a legal and policy framework, along with the above noted supports, are key elements of supported decision-making. However, there is a tendency to focus on the larger more discrete aspects of decision-making such as financial or medical decision-making. While these are critical, it is important not to lose sight of the fact that it is often the multitude of small, day-to-day decisions that reflect the value of autonomy and are essential to quality of life. Unless practice on the ground can embrace supported decision-making on this day-to-day level, then the true value of the right of people with disability to make their own decisions will be muted. Finally, to effectively implement the right to make decisions, the focus should not only be on questions of diagnosis or disability, but on broadly defined personal identity – a person's narrative and life plan – who they are, where do they come from, and where do they want to go (Stainton, 2016)?

Much support for decision-making occurs at the day-to-day level and principally within the informal interpersonal relations in civil society and family, as well as the more formal relations between

clients and disability support workers at the front-line of service provision, rather than under legal mandate. However, very few jurisdictions have enacted specific supported decision-making laws that provide a formal legal and policy framework for this to occur (Carney et al., 2019).

## 4 Supported decision-making in Australia

Upon the ratification of the CRPD, Australia made an Interpretative Declaration in relation to article 12, stating:

Australia declares its understanding that the CRPD allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards. (Convention on the Rights of Persons with Disabilities: Declarations and Reservations (Australia), opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008)).

An interpretative declaration is not a binding reservation. In contrast to a reservation an interpretative declaration does not purport to modify the legal effects of any treaty or provision in a treaty in its application to the state that is making the interpretative declaration. Thus, a state (such as Australia) remains bound to the original treaty or provisions. At least publicly though they can demonstrate a different interpretation.

The National Disability Strategy is the main mechanism for the implementation of the CRPD in Australia. The CRPD principles are also reflected in the *Australian Human Rights Commission Act 1986* and in the mechanisms for the delivery of services to people with disability (such as the NDIA and NDIS Legislative Scheme) (AIHW 2020). But note that it is *individual states* who are responsible for guardianship and mental health laws and thus have the largest impact on directly removing substitute decision-making regimes.

The ALRC (2014) noted that the subsequent *General Comment 1* (United Nations, 2014) stating unequivocally that substitute decision-making schemes like guardianship must be abolished is provided merely 'by way of guidance' and is not binding on Australia (48 [2.56]). The ALRC also decided not to recommend withdrawing Australia's Interpretive Declaration as called for by the Committee of the CRPD, remarking that, notwithstanding any 'confusion ... or negative messaging' that it may carry, '[i]nsofar as the Declaration is simply stating that there are occasions when a person may be appointed to act on behalf of another – as a substitute – the ALRC considers that this is a correct understanding of the CRPD' (ALRC, 2014 57 [2.96]–[2.97]).

The ALRC observed that contention over the 'hard cases' – where a person's will and preference is hard to discern directly from them – should not be a barrier to building law and legal frameworks that 'signal the paradigm shift of the CRPD towards supported decision-making in practice, as well as in form'. Some room for fully supported ('representative') decision-making should remain (ALRC 2014, Chapter 2 [2.116], [10.21]).

Despite the ALRC removing the term 'substituted decision-making', adopting the term 'representative decision-making' instead to signal a shift towards compliance with article 12 of the CRPD, Callaghan (2016) argues representative decision-making is still substituted decision-making. However, it is attenuated by the need to have the person's will, preferences, and rights at the centre of the decision-making process as the object towards which any decision made by the proxy must draw (ALRC 2014, 78 [3.58]–[3.62]).



Where the hard cases exist, the application of supported decision-making may be criticised as relying on a 'legal fiction' by suggesting that the will and preferences of a person can always be ascertained by using the 'best interpretation of will and preferences' approach. However, as Alston (2017) observes, it is not unusual for the law to adopt legal fictions in the pursuit of important societal aims – in this case, ensuring that people with severe cognitive impairment retain their personhood and remain central to decision-making, if only in the minds of those supporting them.

The ALRC recommended an obligation on supporters to try to develop a person's decision-making ability (ALRC 2014, 105). In Australia, attention has turned to the types of programs, practices, and systems necessary to deliver supported decision-making, understood either as a process of supporting a person with decision-making or a means of bringing their will and preference to the centre of any substituted decision-making (Bigby et al., 2017a).

However, Bigby and Douglas (2020) argue that such systems and approaches have so far done little to redress existing inequalities, and those with strong family support do better in accessing individualised resources. Bigby and Douglas (2020a) argue that many people with cognitive disabilities simply do not possess the type of social capital needed to take advantage of opportunities for decision-making in the emerging individualised funding and service systems, such as under the Australian National Disability Insurance Scheme (NDIS).

It is important to note that all Australian jurisdictions have, since CRPD ratification, either completed a review of their guardianship and trustee legislation, or are in the process of doing so, and recognise in some manner, principles around self-determination and human rights. Substitute decision-making is retained as a last resort, like all international jurisdictions. Similarly, all jurisdictions either have reviewed or are in the process of reviewing their mental health legislation. There has been further legislative and policy review throughout Australia in regards to related matters such as restrictive practices, advanced health care directives, and powers of attorney.

## 5 Evidence for best practice

As noted above in Section 1.6, the empirical evidence-base for what works with supported decision-making in both formal and informal spheres is somewhat lacking. Little is known about the delivery or practice of supported decision-making as most articles and reviews are *not* empirically orientated (Bigby et al., 2017). Douglas and Bigby (2020) argue that until recently, the limited empirical investigation into the practice of support for decision-making has meant that our current tools to guide support have been largely based on ideology, principles drawn from social, health, and legal professional practices, or practice wisdom rather than empirical evidence.

Nevertheless, while of variable depth, the body of research that is available examining the practice of support for decision-making illustrates its complexity, and the importance of both a positive support relationship whereby the supporter/s hold the individual as central to the decision-making, and of context and ongoing commitment to the preferences and changing needs of the individual (Bigby et al., 2017).

### 5.1 A person-centred approach

One place to start when considering how a best practice supported decision-making policy or program may look, is through the consideration of a person-centred approach to program design and implementation (see Productivity Commission, 2019, 173):

**A person-centred approach is underpinned by several interrelated principles.**

- **Putting the person at the centre:** the main objective of disability policy and planning is to improve the lives of people with disability, not simply to provide disability services.
- **Autonomy and agency**, including:
  - choice and control — people with disability are able to take control of their own lives and make genuine choices
  - self-determination — people with disability are actively involved in decision-making processes that affect their own lives, including in the development and evaluation of disability policy
  - independence — people with disability are empowered to maintain independence in their daily lives.
- **Social inclusion:** people with disability are able to participate and engage meaningfully in their communities and in wider society. This includes building community capacity and **networks for people with disability, their families and carers.**
- **Citizenship:** people with disability are active citizens, capable of contributing to society and are entitled to the support they need to function as citizens.

A further approach to thinking about the nature of best practice is to identify the **indicators** of a quality outcome for a supported decision-making process (formal or informal). Indicators can be general or highly specific to the context and the individual. Indeed, a key principle of SDM is that it is highly individualised; different persons have different decisions, give weight to different decisions, and require different levels of support even within decisions. So, it may be difficult to

prescribe generic one size fits all quality outcome indicators. Having said that, Kohn and Blumenthal (2014, s42) suggest asking the following **questions** which incorporate two broad indicators to demonstrate whether the support process has been effective:

1. Does a decision 'arrived at through SDM truly express and effectuate the preferences of the principal'? and
2. Is the decision 'more beneficial to the principal than a decision made alone, or than the decision of some proxy, whether formally or informally appointed'?

The above questions can be incorporated at all stages of the SDM planning, design, implementation and evaluation. They can be either asked directly, or used to influence how processes are designed. For example:

- How does the design of the SDM framework help answer Question 1?
  - Has the supporter identified will and preferences?
  - How does the supporter record this?
  - What is the *process* used to support a person to make a decision? What are the *steps* that must be taken?
  - Has the supporter recorded the outcome of each step in the process? How?
- Question 2 goes to efficiency, as well as indicating a deeper awareness of the actual needs of the person requiring decision-making support. Therefore, consideration should be given to:
  - Do/Did the person need the supporter?
  - What *types* of decisions does the person require support with?
  - Could the supporter assist this time? Why/why not?
  - Was a decision made?

## 5.2 Identified evidence-based good practice principles

Despite the limitations noted previously, there are some consistent findings about the nature of good practice in decision-making support that facilitates participation by people with cognitive disabilities in the decision-making process. These *principles* can be adapted and applied across multiple domains, including guardianship, mental health, health, justice, and child protection.

Underpinning what the authors of this review consider to be good practice is the classic observation from Beamer and Brookes (2001) that when seeking to understand the nuance of supported decision-making, it can be differentiated from substitute decision-making in the following way:

The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices. (Beamer & Brookes, 2001, 4)

While Beamer and Brookes (2001) do not mention the role of will and rights in the above context, the observation is none the less pertinent. Supported decision-making is not about capacity, but a presumption that individuals are always capable of communicating and expressing our preferences – but may need some assistance from time to time. Furthermore, the concept of a continuum is recognised – a person’s understanding of decision-making process can vary from decision to decision, and context to context. It is equally wrong to think of a person’s position on the continuum of requirement for decision-making support as fixed in time.

The current desktop review identified the following as elements of good practice, compliant with CRPD and consistently identified across the literature and tied to an evidence-base (Bigby et al., 2017; Bigby et al., 2019; Bigby & Douglas, 2020a; Bigby & Douglas, n.d.; Browning et al., 2020; Douglas & Bigby, 2020; Watson et al., 2017; Mirfin-Veitch, 2016). Some of the elements overlap but are included separately for completeness. A common cross-cutting theme is the importance of a supporter taking the time to get to know the person they are supporting:

The following key elements of good decision-making have been identified as 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.

In cases where a person requiring decision-making support is reliant on support coming via an agency rather than their informal network, research about the actual practice of providing support for decision-making points to the importance of trusting relationships and the lengthy and time-consuming nature of providing good support. This suggests the need for longevity of decision maker/supporter relationships and by extension the longevity of programs that can recruit, train and support supporters. The lack of evidence about effective models for delivering support for decision-making, coupled with the legislative, organisational, and familial complexity of providing support, further highlight the need for long-term services and supports integrated across multiple systems and interfaces (Bigby et al., 2017).

The role of supporters is to explain issues, explore options and support the expression of will and preferences (Carney & Beaupert, 2013). They may engage others in decision-making processes, make agreements that give effect to decisions, or implement decisions (Bigby & Douglas, 2020). Supporters' roles with people with more severe intellectual disability may extend to interpreting signs and preferences, ascribing agency to a person's actions, or co-constructing will and preferences or decisions (Bigby & Douglas, 2020a). Browning et al. (2020) note that supporting a person with decision-making can be described as 'assistive thinking' and providing a 'cognitive prosthesis'.

Supported decision-making is not a one-size-fits-all approach an agency or worker can take – successful support requires a deep understanding about the need to tailor communication and

presentation of abstract concepts to reflect the experiences of individuals being supported. This suggests the importance of embedding these areas of knowledge in foundational training of support workers and the provision of resources about decision support targeted at workers or families (Bigby et al., 2019).

The importance of positive perceptions of a person's ability to lead self-directed lives is not only reflected in the research literature, but in principles guiding contemporary law and policy. For example, the CRPD promotes an assumption of decision-making capacity, and the United Kingdom *Mental Capacity Act 2005* (MCA), has, as its first principle, a need for supporters to assume a person has decision-making capacity. This focus on the need for a change in supporter attitudes, rather than a change in people with disability, is reflected in the social model of disability, embedded within the CRPD.

The negative impact of staff with inadequate communication skills, knowledge of the impact of intellectual disability, or awareness of their own values, was evident in a number of studies (Bigby et al., 2019). In some instances, supporters actively shaped decisions to reduce risk or ensure an outcome they perceived to be in the best interest of the person with intellectual disability. Research suggests that training in self-reflection and review may provide useful tools to help supporters to become self-aware and minimise practices of undue influence (Browning et al., 2020).

### 5.3 Practice point: Understanding safeguards

It is important to gather rigorous evidence of what works (and what does not work) to ensure that the will, preferences and rights of people with cognitive disabilities are at the centre of decision-making support processes and are accurately reflected in final decisions made (Douglas & Bigby, 2020). Doubts have been raised about the capacity of such schemes to deliver their intended benefits across the full range of people with cognitive disabilities. The limited empirical evidence about the effectiveness of supported decision-making schemes or safeguarding mechanisms, together with the vulnerability of people with cognitive disabilities may account for hesitancy about its more widespread and formalised adoption (Bigby & Douglas, 2020a). Concern has also been raised around confusion over the legal standing of informal supporters, including personal liability issues, and the risk that decision-support can take on a particular paternalistic form (Bigby et al., 2019).

Several studies have identified the restrictive impact that staff or family expectations can have on decision-making opportunities (Bigby et al., 2019). Bigby and Douglas (2020a) suggest we can no longer rely on unregulated informal support for decision-making. They note that a significant amount of research suggests the inequities caused by the 'lottery of social capital', and evidence that a person's will and preferences are often overridden in an informal network, means that direct intervention or supervision may be required to ensure justice.

As the emerging body of evidence about decision support suggests, informal support for decision-making often lacks systematic guidance to supporters, resources to build their capacity or mechanisms for accountability, and runs the risk of being undermined by conflict or uncertainty, paternalism and becoming simply informal substitute decision-making (Bigby, 2017b; Bigby & Douglas, 2020a). Evaluations of small pilot decision support programs in Australia do demonstrate the benefits of support to supporters through training or individual consultations, do show promise,

though those training packages are often based on expert opinion and practice wisdom rather than rigorously developed empirical evidence (Bigby & Douglas, 2020a).

Lashewicz et al. (2014) have cautioned that it can be difficult to disentangle the voice of the person from the families, particularly in difficult advocacy situations. This speaks to the need for education on what it means to be a supported decision maker and for a system of safeguards to ensure that the person's views are not misrepresented or suppressed (see Stainton, 2016). Carney questions whether the risk of misreading the will, preferences and rights of someone with a disability can adequately be allayed by capacity-building targeted on supporters (Carney, 2017b).

While safeguards are critical in formal arrangements, what type of safeguards and how to best introduce these to the realm of informal support networks to protect a vulnerable person is fast becoming a wicked problem. In the absence of data, Kohn et al. (2013) argue that:

[I]t is impossible to know whether supported decision-making actually empowers persons with cognitive and intellectual disabilities. Furthermore, there is reason to be concerned that supported decision-making might actually have the opposite effect, disempowering such individuals or making them more vulnerable to manipulation, coercion, or abuse (Kohn et al., 2013, 1114).

They argue further that:

There is reason to be concerned that supported decision-making may allow largely unaccountable third parties to improperly influence the decisions of persons with disabilities, thereby disempowering persons with disabilities and undermining their rights (Kohn et al., 2013, 1157).

Kohn and Blumenthal (2014, s41) clarified this concern. As they see it:

The most serious concern in terms of process is the potential for coercion or other inappropriate influence by a representative or supporter. In informal arrangements such as SDM, which may occur in private and with less accountability than formal procedures such as guardianship, the potential for financial or other abuse likely increases.

In Australia, Barry and Sage-Jacobson (2015, 14–15) argue that if 'sufficient safeguards concerning education and supervision of supporters are absent from legislation, supported decision-making may simply become a form of *surrogate guardianship*' (emphasis added).

Anna Arstein-Kerslake (2016, 90) has also argued along similar lines that there needs to be a clear-eyed acknowledgment of the support-supporter relationship 'as one of influence and interaction in order to put in place the essential safeguards to ensure genuine choice for the individual and realisation of her will and preferences'. Provision of unregulated informal support places few expectations on supporters and offers little guidance about supporting decision-making. At times, this has led to confusion about the legal standing of informal supporters; a tendency to resort to informal substitute decision-making or undue paternalism; and decisions that reflect the values of others, which are made in haste, are driven by resource issues, or are contrary to values and rights embedded in policy (Douglas et al., 2015).

Most recently, Bigby and Douglas (n.d.) have acknowledged the wicked problem as argued by Kohn et al. (2013; 2014) and others. They argue that to be true to purpose, supported decision-

making relies on the skills and integrity of supporters to explore options and interpret preferences. They acknowledge there is significant potential for undue influence and conflicts of interest as supporters are challenged to put aside their own values and avoid their interests interceding in practice, especially where they have a stake in decision outcomes.

Relatedly, what to do when it is not possible to obtain the will and preferences of a person has been highlighted as a significant issue within the debates relating to article 12 (Mirfin-Veitch, 2016). It is at the heart of the tension surrounding the acknowledgement that there will be on occasion hard cases (ALRC, 2014).

Finally, supported decision-making requires a network of people who know a person intimately as an individual and whose relationship is based on trust and mutuality rather than just a professional or contractual relationship (Stainton, 2016). The core of this network is usually families and close friends. The challenge is, and always has been, how does one develop and sustain such networks where these are absent or have been diminished (Stainton, 2016).

## 5.4 Practice point: Understanding dignity of risk

'Dignity of risk' is defined as 'the placement of greater value on respecting the individual's right to decide, even when a person's choices may seem foolish to others, than on protecting the 'best interests' of the individual' (Hommel, 1996). The term dignity of risk was first used by Robert Perske (1972) in relation to people with disability living in supported care environments. The concept was developed as a reaction to the perceived over-protective safeguards and paternalistic nature of supported living arrangements at that time. Wolpert (1980) argues that prioritising safeguards over an individual making independent decisions constitutes an unacceptable attack on personal rights and freedoms and negatively impacts on that person's sense of worth and identity.

Dignity of risk has now been recognised in several guardianship and trustee legislative schemes in Australia and internationally. For example, the *Mental Capacity Act 2005* (United Kingdom) (MCA) which came into force in 2007 in England and Wales, and the *Scottish mental capacity legislation (Adults with Incapacity (Scotland) Act, Scottish Government, 2000, 2008)*, along with similar legislation in Northern Ireland, all stipulate that it cannot be concluded that a person is unable to make a particular decision **because he or she makes what might be an unwise decision** (Beadle-Brown, 2015).

The MCA is instructive of this. There are five core principles outlined in Section 1 of the MCA. Section 1(4) is focused on dignity of risk:

The principles

1. The following principles apply for the purposes of this Act.
2. A person must be assumed to have capacity unless it is established that he lacks capacity.
3. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.



4. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
5. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
6. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Similar explicit provisions are seen in some Australian legislation; however, this is not universal. The Victorian *Guardianship and Administration Act 2019* (Vic) at section 5(4)(d) states, like the MCA:

[I]t should not be assumed that a person does not have decision-making capacity in relation to a matter merely because the person makes a decision that, in the opinion of others, is unwise.

The key challenge facing systems and supporters with dignity of risk is balancing it with a duty of care that may be owed by an agency for example (such as a Public Guardian or Public Trustee). While unduly restricting risk can result in a diminished quality of life (and hence 'harm'), any risk taking should be 'reasonable' (Marsh & Kelly, 2018; Ibrahim & Davis, 2013). A key issue here is proportionality. What is proportional is likely to be determined on a case-by-case basis. Risk cannot be avoided completely, and we need to be aware of the harm that can occur by not allowing risk.

## 6 Discussion

The CRPD Committee has stressed the immediacy of the requirement of the removal of substitute decision-making schemes, and the adoption of supported decision-making approaches on the basis that equal recognition before the law identified in article 12 CRPD is a civil right and civil rights must take effect upon treaty ratification (United Nations, 2014).

As Stavert (2018) has argued, however, quite apart from abolishing laws and practices that permit substitute decision-making, the actual task of introducing widespread supported decision-making regimes across all layers of public (let alone private) life in a manner that fulfils article 12 CRPD requirements as stipulated in the *General Comment 1* (United Nations, 2014) should not be underestimated. The level of accompanying resourcing and policy, legal and practice culture shift that is required to effect such a change should also not be downplayed. To continue in an ad-hoc or piecemeal manner though is of greater cost.

A focus on operationalising supported decision-making provides a framework for undertaking the above task in a structured, efficient, incremental and informed manner. There is a danger, as reflected in the literature, that supported decision-making becomes overly complicated in the pursuit of perfection. This is not conducive to operationalising supported decision-making.

Overly fixating on the experience of the hard cases is potentially detrimental – it has the ability to subsume a disproportionate number of resources (broadly identified) grappling with a philosophical matter that may on the one hand not really exist, and on the other, if it does, realistically it can have no practical application. As the ALRC argues, there will always likely be hard cases. Attempting to change this (at least in the current paradigm) is fruitless and detracts from where the most efficient use of resources can be directed.

At its core, supported decision-making is about taking the time to listen and communicate (Arstein-Kerlske et al., 2017). From the perspective of self-determination, good support for decision-making is crucial. It enables the will and preferences of a person who requires decision-making support to be central to their decisions and increases their control over their own lives. In turn, this has been demonstrated to positively affect the self-identity, psychological wellbeing, and quality of life of people with cognitive disabilities (Douglas et al., 2015).

Personal support networks are a critical ingredient to supported decision-making and yet most jurisdictions lack policy, funding, and community capacity for developing and maintaining support networks (Stainton, 2016). If you require decision-making support and you have an existing family and social network to assist, you are in a much better position to grapple with the increasing complexity of accessing funding and services, compared with a person who lacks an existing strong social/family support network. Consider as well that people with disability are at greater risk of poverty and social isolation and social exclusion. Combatting this isolation and exclusion should be of primary concern for policy makers.

Balanced with this is a need to recognise the organic nature of decision-making in policy and practice. How this plays out in the context of disability is difficult to conceive of; however, at a minimum, the implication from the research is care must be taken to avoid wrapping people up in systems and services, also referred to as 'over servicing'. A point for policy makers is that the most

efficient uses of resources, and way of promoting self-determination will come by targeting products and services, avoiding duplication, reducing complexity, and allowing for choice as to the level of adoption and engagement by the end user.

There are a number of challenges to reform in the sense of changing community and institutional attitudes and practices away from questions about whether a person has capacity to decide, and towards normalising the presumption that everyone *has* capacity and will be provided with support to assist them to make a decision if required. Reform may be impeded by ingrained societal attitudes of paternalism and ableism. The literature is consistent in highlighting that social perceptions of disability remain an obstacle to wide-scale recognition of the right to exercise legal capacity and the role of supported decision-making in realising that for some (Watson, 2016; Mirfin-Veitch, 2016; Backman, 2020).

A key theme to emerge from the literature is a need to shift our discussion explicitly to identifying what is meant by success and quality in respect of supported decision-making. Attention should be given to establishing the *criteria* of what success looks like – for a supporter, for a person requiring support, and for an agency. Judging what is a good quality decision is difficult (Bigby & Douglas, n.d.) but it is important to challenge suggestions put forward by some that supported decision-making models may not necessarily lead to different outcomes than adult guardianship once an account is taken of other rights (Carney, 2017b).

Similarly, a focus on developing criteria for success along with an emphasis on operationalising supported decision-making will go a long way to addressing ongoing concerns such as those raised by Bigby and Douglas (n.d.) about the low level of empirical evidence showing ‘fidelity to purpose’ of supported decision-making, and whether supported decision-making can deliver on promises of both empowerment and safeguarding.

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 an extensive face-to-face stakeholder consultation process. It identifies a clear scope to broaden the evidence-base for disability, human-rights and supported decision-making policy making.

# 7 References

## 7.1 Guides, frameworks, United Nations references

- Allens Linklaters, Queensland Advocacy Inc, Queensland Law Society (20xx). 'Queensland Handbook for Practitioners on Legal Capacity'.
- Auckland Disability Law (2016). 'Supported Decision-making Easy Read guide'.
- Australian Competition & Consumer Commission (ACCC) (2011). 'Don't take advantage of disadvantage. A compliance guide for businesses dealing with disadvantaged or vulnerable consumers'.
- Bigby C, & Douglas J (2015). Support for decision-making – A practice framework. Living with Disability Research Centre, La Trobe University.
- Brophy L, McSherry B, Kokanovic R, Moeller-Saxone K, & Herrman H (20xx). 'Guidelines for Supported Decision-Making in Mental Health Services'.
- Council for Intellectual Disability (2020). 'Communications Tips' (Fact Sheet, CID, May 2020).
- Disability Rights Maine (2019). 'Supported Decision-Making. A User's Guide for People with Disabilities and Their Supporters'.
- Down Syndrome Australia (20xx). 'Decision-making, guardianship, and people with Down syndrome'.
- Down Syndrome Australia. (20xx) 'Supported decision-making and Down syndrome'.
- Duffield L, Koritsas S, Watson J, & Hagiliassis N (2016). 'Decision-making support for people with cognitive disability. A guide for disability workers'. Melbourne Scope (Aust).
- Gooding P, Fleming L, Watson J, Koritsas S, Cuzzillo C, & Hagiliassis N (2016). 'Decision-making support: An educational resource for legal professionals working with people with cognitive disability'. Melbourne: Scope (Aust).
- IHC New Zealand (20xx). 'Research Report. What does helpful supported decision-making look like to people with intellectual disabilities?'
- IHC New Zealand (20xx). 'Advocacy Toolkit. For Supporters of People with an Intellectual Disability'.
- IHC New Zealand (20xx). 'Supporting Decision-Making. A Guide for Supporters of people with Intellectual Disability'.
- Judicial College of Victoria (2020). 'Guide to the Guardianship and Administration Act 2019 (Vic)'
- Kokanovic R, et al. (n.d). 'Fact Sheet 3: Practices to Improve Supported Decision-Making in Mental Health Services' (Fact Sheet, Health Direct, n.d.).
- Maker Y, Callahan A, McSherry B, Paterson JM, Brophy L, & Arstein-Kerslake A (20xx). 'Consumers with Cognitive Disabilities. Top Five Tips for Improving Access and Support'.

- Maker Y, Callahan A, McSherry B, Paterson JM, Brophy L, & Arstein-Kerslake A (20xx). 'Improving Access and Support for Consumers with Cognitive Disabilities. A Guide for Retailers'.
- Maker Y, Callahan A, McSherry B, Paterson JM, Brophy L, & Arstein-Kerslake A (n.d.). 'Enhancing Access and Support for Water Customers with Cognitive Disabilities. A Guide for Water Businesses.
- Maker Y, Paterson JM, McSherry B, Brophy L, Arstein-Kerslake A, Callahan A, & Teo E (2018). Thanks a bundle. Improving support and access to online telecommunications products for consumers with cognitive disabilities.
- National Disability Services (20xx). 'People with Disability and SDM. A Guide for NDIS Providers in NSW'.
- National Disability Service (20xx). 'People with Disability and Supported Decision-Making and the NDIS'.
- New Zealand Government, Ministry of Social Development (2020). 'Supported decision-making'.
- NSW Government Department of Communities & Justice (DCJ) (2020). 'Capacity Toolkit'.
- NSW Government Department of Family & Community Services (FACS) (2015). 'My life, my decision. A handbook for decision makers'.
- NSW Government Department of Family & Community Services (FACS) (2016). 'Decision-making and Consent Guidelines' (Policy).
- NSW Government Department of Family & Community Services (FACS) (2019). 'Supported Decision-making. A handbook for facilitators'
- NSW Government Department of Family & Community Services (FACS). (2019) 'Supported Decision-making. A handbook for supporters'.
- Queensland Government Department of Justice and Attorney-General (DJAG) (2020). 'Queensland Capacity Assessment Guidelines 2020'.
- Queensland Office of the Public Guardian (OPG) (2017). 'Structured Decision-Making Framework Policy'.
- Ramcharan P, Leighton D, Moors R, Laragy C, Despott N, & Guven N (2013). 'It's My Choice! Toolkit', Inclusion Melbourne/RMIT University, Melbourne.
- Sinclair C, Field S, & Blake M (2018). Supported decision-making in aged care: A policy development guideline for aged care providers in Australia. (2nd Edition) Sydney: Cognitive Decline Partnership Centre.
- Sinclair C, Field S, Williams K, Blake M, Bucks R, Auret K, Clayton J, Kurrle S (2018). Supporting decision-making: A guide for people living with dementia, family members and carers. Sydney: Cognitive Decline Partnership Centre.
- South Australian Office of the Public Advocate (2011). 'Developing a Model of Practice for Supported Decision-making' (Supported Decision-making Practice Manual v1.4 June 2011) [http://www.opa.sa.gov.au/resources/supported\\_decision\\_making](http://www.opa.sa.gov.au/resources/supported_decision_making).
- Stavert J (2016). Supported Decision-Making: Good Practice Guide.

- United Nations (2006). *Convention on the Rights of Persons with Disabilities*, 13 December 2006, A/RES/61/106.
- United Nations, Committee on the Rights of Person with Disabilities (2014). *General Comment No. 1. Article 12: Equal recognition before the law*, CRPD/C/GC/1.
- United Nations, Department of Economic and Social Affairs, Office of the United Nations High Commissioner for Human Rights and Inter-Parliamentary Union (2007). *Handbook for Parliamentarians – From Exclusion to Equality: Realising the Rights of Persons with Disabilities* (United Nations, 2007).
- Victorian Government Department of Human Services (DHS) (2012). 'Supporting decision-making. A guide to supporting people with a disability to make their own decisions'.
- Victorian Office of the Public Advocate (OPA) (2018), 'Guide to NDIS decision-making. When a decision can be made by, with, or for an adult with significant cognitive disability'.
- Victorian Office of the Public Advocate (OPA) (2018). 'Side by Side: A guide for people wanting support to make decisions' (supportive attorney).
- Victorian Office of the Public Advocate (OPA) (2020). 'Supported Decision-Making in Victoria'.
- Western Australia's Individualised Services (WAIS) (20xx). 'Supported Decision-making'.

## 7.2 Reports

- ACT Disability, Aged and Carer Advocacy Service (ADACAS) (2016). Supported Decision-making, Psychosocial Disability and the National Disability Insurance Scheme (February 2016).
- ACT Disability, Aged and Carer Advocacy Service (ADACAS) (2018). Evaluation Report of the Link and Learn Supported Decision-Making Project. A Report made to the Community Services Directorate, Office for Disability, ACT.
- ADACAS (2013). Spectrums of Support. A Report on a project Exploring Supported Decision-making for People with Disability in the ACT.
- Australian Law Reform Commission (2014). Equality, capacity and disability in Commonwealth Laws. Final Report. ALRC Report 124, August 2014.
- Bach M, & Kerzner L (2010). A New Paradigm for Protecting Autonomy and the Right to Legal Capacity. Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice.
- Bach M, & Kerzner L (2020). Supported Decision-making – A Roadmap for Reform in Newfoundland and Labrador: Final Report. Toronto: Institute for Research and Development on Inclusion and Society (IRIS)
- Bigby C, Whiteside M, & Douglas M (2015). Supporting People with Cognitive Disabilities in Decision-making – Processes and Dilemmas. Melbourne: Living with Disability Research Centre, La Trobe University.
- Bullen J, Johnson K, & Purcal C (2016). Supported Decision-making Project, Phase Two Evaluation: Evaluation Plan. Sydney: Social Policy Research Centre, UNSW Australia.

- de Sande, C A, Ros, B F, i Chavero, J M S, Marroyo, L, Leotti, P, Karagouni, S, Hänninen, K and Churchill, J (I-DECIDE Partnership) (2018). From 'Guardians' to 'Supporters': Supported Decision-making in Service Provision for Persons with Disabilities. This is a report by the I-DECIDE partnership, coordinated by the European Association of Service providers for Persons with Disabilities (EASPD).
- Douglas J, Bigby C, & Smith E (2020). Final Report. Building capability to support client decision-making. TAC Project No: T005 (April 2020).
- ENNHRI. (2020) Implementing supported decision-making, Developments across Europe and the role of National Human Rights Institutions (8 June 2020).
- Harding R, & Tascioglu E (2017). Everyday Decisions Project Report. Supporting Legal Capacity through Care, Support and Empowerment.
- IHC (20xx). Research report: What does helpful supported decision-making look like to people with intellectual disabilities?
- Killeen J (2016). Supported Decision-making: Learning from Australia. Rights for Person with Cognitive Disabilities. Winston Churchill Memorial Trust.
- Kokanovic R, Brophy L, McSherry B, Hill N, Johnston-Ataata K, Moeller-Saxone K, & Herrman H (2017). Options for Supported Decision-Making to Enhance the Recovery of People Experiencing Severe Mental Health Problems. Melbourne: Melbourne Social Equity Institute, University of Melbourne.
- Lashewicz B, Mitchell J, Salami E, & Cheuk S (2014). Understanding and addressing voices of adults with disabilities within their family caregiving contexts: Implications for capacity, decision-making and guardianship (Toronto, Canada: Law Commission of Ontario).
- Law Commission of Ontario (2017). Legal Capacity, Decision-making and Guardianship: Final Report (Toronto, Canada: Law Commission of Ontario, March 2017).
- Law Council of Australia (2020). National Disability Strategy Submission (30 October 2020).
- Mirfin-Veitch B (2016). Exploring Article 12 of the United Nations Convention on the Rights of Persons with Disabilities: An Integrative Literature Review. Donald Beasley Institute: Dunedin.
- New South Wales Law Reform Commission (NSWLRC) (2018). Review of the Guardianship Act 1987. Report 145, May 2018.
- NHMRC Cognitive Decline Partnership Centre (CDPC) (2019). Supported Decision-Making in Dementia Care: Final Project Report. Sydney: NHMRC Cognitive Decline Partnership Centre.
- Office of the Public Advocate, Systems Advocacy (Qld) (2014). Autonomy and decision-making support in Australia. A targeted overview of guardianship legislation.
- Office of the Public Advocate, Systems Advocacy (Qld) (2014). A journey towards autonomy? Supported decision-making in theory and practice. A review of the literature.
- Office of the Public Advocate (Qld) (2016). Decision-making support and Queensland's guardianship system. A systemic advocacy report.

- Purcal C, Hill T, Johnson K, & Kayess R (2017). Evaluation of the Supported Decision-making Phase 2 (SDM2) project: Final report.
- Tasmania Law Reform Institute (2018). Review of the *Guardianship and Administration Act 1995* (Tas). Final Report No 26, December 2018.
- VALID and Office of the Public Advocate (Vic) (2017). The OVAL Project. Volunteer Programs of Support for Decision-Making: Lessons and recommendations from the OVAL Project.
- Van Puymbrouck L (2017). Supported decision-making in the United States: A white paper by CQL. The Council on Quality and Leadership. Towson, MD: CQL.
- Wallace M (2012). Evaluation of the Supported Decision-Making Project (Report prepared for Office of the Public Advocate South Australia).
- Westwood Spice (2015). My life, my decision. An independent evaluation of the Supported Decision-making Pilot.

### 7.3 Journal articles, book chapters

- Alston B (2017). 'Towards Supported Decision-Making: Article 12 of the Convention on the Rights of Persons with Disabilities and Guardianship Law Reform' *Disability, Rights and Law Reform in Australia* 35(2):21–43.
- Arstein-Kerslake A (2016). 'An Empowering Dependency: Exploring Support for the Exercise of Legal Capacity' *Scandinavian Journal of Disability Research* 18(1):77–92.
- Arstein-Kerslake A, & Flynn E (2015). 'The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality before the Law' *The International Journal of Human Rights* 20(4):471–90.
- Arstein-Kerslake A, Watson J, Browning M, Martinis J, & Blanck P (2017). 'Future direction in supported decision-making' *Disability Studies Quarterly* 37(1).
- Backman S (2020). 'The Right to Legal Capacity for Canadians with Disabilities: A Quest for Dignity, Equality, and Autonomy' *McGill Faculty of Law, International Human Rights Internship program, Working Paper Series* 8(1) Fall 2020.
- Barry L, & Sage-Jacobson S (2015). 'Human Rights, Older People and Decision-making in Australia' *Elder Law Review* 9.
- Beadle-Brown J (2015). 'Supported Decision-making in the United Kingdom: Lessons for Future Success' *Research and Practice in Intellectual and Developmental Disabilities* 2(1):17–28.
- Beamer S, & Brookes M (2001). Making decisions. Best practice and new ideas for supporting people with high support needs to make decisions. London: Values into Action.
- Bigby C, & Douglas J (2020a). 'Supported Decision-making' in Stancliffe, R., Wehmeyer, P., Shrogran, K. (Eds) Choice, preference, and disability: Promoting self-determination across the lifespan. New York: Springer.
- Bigby C, & Douglas J (n.d.). 'Unpacking the Complexities of the Practice of Support for Decision-making' Book Chapter (Forthcoming).



- Bigby C, Douglas J, Carney T, Then S–N, Wiesel I, & Smith E (2017). 'Delivering decision-making support to people with cognitive disability – What has been learned from pilot programs in Australia from 2010 to 2015' *Australian Journal of Social Issues* 52:222–240.
- Bigby C, Douglas J, Smith E, Carney T, Then S-N, & Wiesel I (n.d.a). "I used to call him a non-decision-maker – I never do that anymore': Parental reflections about training to support decision-making of their adult offspring with intellectual disabilities' (Forthcoming)
- Bigby C, Douglas J, Smith E, Carney T, Then S-N, & Wiesel I (n.d.b). 'Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences' (Forthcoming).
- Bigby C, Whiteside M, & Douglas J (2019). 'Providing support for decision-making to adults with intellectual disability: Perspectives of family members and workers in disability support services' *Journal of Intellectual & Developmental Disability* 44(4):396–409.
- Bould, E, Bigby, C, Iacono, T, & Beadle-Brown, J (2019). 'Factors associated with increases over time in the quality of Active Support in supported accommodation services for people with intellectual disabilities: A multi-level model. *Research in Developmental Disabilities* 94: 103477
- Browning M, Bigby C, & Douglas J (2014). 'Supported Decision-making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice' *Research and Practice in Intellectual and Developmental Disabilities* 1(1):34–45.
- Browning M, Bigby C, & Douglas J (2020). 'A process of decision-making support: Exploring supported decision-making practice in Canada' *Journal of Intellectual & Developmental Disability*.
- Burgen B (2016). 'Reflections on the Victorian Office of the Public Advocate supported decision-making pilot project' *Research and Practice in Intellectual and Developmental Disabilities* 3(2):165–181.
- Callaghan S, & Ryan CJ (2016). 'An Evolving Revolution: Evaluating Australia's Compliance with the Convention on the Rights of Persons with Disabilities in Mental Health Law' *UNSW Law Journal* 39(2):596–624.
- Carney T (2013). 'Participation and service access rights for people with intellectual disability: A role for law?' *Journal of Intellectual and Developmental Disability* 38(1): 59–69.
- Carney T (2015a). 'Supported decision-making for people with cognitive impairments: An Australian perspective' *Laws* 4(1):37–59.
- Carney T (2015b). 'Supporting People with Cognitive Disabilities with Decision-making: Any Australian Law Reform Contributions?' *Research and Practice in Intellectual and Developmental Disabilities* 2(1):6–16.
- Carney T (2017a). 'Prioritising Supported Decision-Making: Running on Empty or a Basis for Glacial-To-Steady Progress?' *Laws* 6(18).
- Carney T (2017b). 'Supported Decision-Making in Australia: Meeting the Challenge of Moving from Capacity to Capacity-Capacity Building?' *Disability, Rights and Law Reform in Australia* 35(2):44–63.

- Carney T, & Beaupert F (2013). 'Public and Private Bricolage – Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making' *UNSW Law Journal* 36(1):175–201.
- Carney T, Bigby C, Then S-N, Smith E, Wiesel I, & Douglas J (n.d.). 'Paternalism to Empowerment: All in the eye of the beholder?' (Forthcoming).
- Carney T, Then S-N, Bigby C, Wiesel I, Douglas J, & Smith E (2019). 'Realising 'will, preferences and rights': reconciling differences on best practice support for decision-making?' *Griffith Law Review* 28(4):357–379.
- Davidson G, Brophy L, Campbell J, Farrell SJ, Gooding P, & O'Brien AM (2016). 'An international comparison of legal frameworks for supported and substitute decision-making in mental health services' *International Journal of Law and Psychiatry* 44:30–40.
- Davidson G, Kelly B, Macdonald G, Rizzo M, Lombard L, Abogunrin O, Clift-Matthews V, & Martin A (2015). 'Supported decision-making: A review of the international literature' *International Journal of Law and Psychiatry* 38:61–67.
- Devi N (2013). 'Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities' *Journal of Law, Medicine and Ethics* 41(4):792–806.
- Douglas J, & Bigby C (2020). 'Development of an evidence-based practice framework to guide decision-making support for people with cognitive impairment due to acquired brain injury or intellectual disability' *Disability and Rehabilitation* 42(3):434–441.
- Douglas J, Bigby C, Knox L, & Browning M (2015). 'Factors that Underpin the Delivery of Effective Decision-making Support for People with Cognitive Disability' *Research and Practice in Intellectual and Developmental Disabilities* 2(1):37–44.
- Flynn E, & Arstein-Kerslake A (2014). 'Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity' *International Journal of Law in Context* 10(1): 81–104.
- Glen KB (2017). 'Piloting Personhood: Reflections from the First Year of a Supported Decision-Making Project' *Cardozo Law Review* 39:495–518.
- Gooding P (2015). 'Navigating the 'Flashing Amber Lights' of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns' *Human Rights Law Review* 14:45–71.
- Gooding P, Anderson J, & Mcvilly K (2017). 'Disability and social inclusion 'Down Under': A systematic literature review' *Journal of Social Inclusion* 8(2):5–26.
- Gordon RM (2000). 'The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making' *International Journal of Law and Psychiatry* 23(1):61–77.
- Harding R, & Tascioglu E (2018). 'Supported Decision-Making from theory to Practice: Implementing the Right to Enjoy Legal Capacity' *Societies* 8(25).
- Hillman A, Donnelly M, Whitaker L, Dew A, Stancliffe RJ, Knox M, Shelley K, & Parmenter TR (2012). 'Experiencing Rights within Positive, Person-Centred Support Networks of People with Intellectual Disability in Australia' *Journal of Intellectual Disability Research* 56(11):1065–1075.

- Hommel PA (1996). 'The More Things Change: Principles and Practices of Reformed Guardianship', in M Smyer et al. (eds), *Older Adults Decision-Making and the Law* (Springer Publishing, 1996) 182-201.
- Ibrahim JE, & Davis M-C (2013). 'Impediments to applying the 'dignity of risk' principle in residential aged care services' *Australasian Journal on Ageing* 32(3):188–193.
- Kanter AS, & Tolun Y (2017). 'The Fight for Personhood, legal Capacity, and Equal Recognition under Law for People with Disabilities in Israel and Beyond' (2017) *Cardozo Law Review* 39:557–608.
- Kayess, R, & French, P (2008). 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' *Human Rights Law Review* 8(1):1-34.
- Knox L, Douglas MJ, & Bigby C (2017). "'I've never been a yes person': Decision-making participation and self conceptualization after severe brain injury' *Disability and Rehabilitation* 39(22):2250–2260.
- Kohn NA, Blumenthal JA (2014). 'A critical assessment of supported decision-making for persons aging with intellectual disabilities' *Disability and Health Journal* 7:S40–S43.
- Kohn NA, Blumenthal JA, & Campbell AT (2013). 'Supported Decision-Making: A Viable Alternative to Guardianship?' *Penn State Law Review* 117(4):1111–1157.
- Lawson, A, & Beckett AE (2021). The social and human rights models of disability: towards a complementarity thesis. *The International Journal of Human Rights*, 2(2): 348-379.
- Maker Y, Arstein-Kerslake A, McSherry B, Paterson JM, & Brophy L (2018). 'Ensuring Equality for Persons with Cognitive Disabilities in Consumer Contracting: An International Human Rights Law Perspective' *Melbourne Journal of International Law* 19(1):178–199.
- Maker Y, Paterson JM, Arstein-Kerslake A, McSherry B, & Brophy L (2018). 'From Safety Nets to Support Networks: Beyond 'Vulnerability' in protection for Consumers with Cognitive Disabilities' *UNSW Law Journal* 41(3):818–845.
- Marsh P, & Kelly L (2018). 'Dignity of risk in the community: A review of and reflections on the literature' *Health, Risk & Society* 20(5–6):297–311.
- Pathare S, & Shields LS (2012). 'Supported Decision-Making for Persons with Mental Illness: A Review' *Public Health Reviews* 34(2):1–40.
- Perske R (1972). 'The dignity of risk and the mentally retarded' *Mental Retardation* 10(1):24–27.
- Peterson A, Karlawish J, & Largent E (2020). 'Supported Decision-making with People at the Margins of Autonomy' *The American Journal of Bioethics*.
- Quinn, G, & Degener T (2002). 'The Moral Authority for Change: Human Rights Values and the World Wide Process of Disability Reform', in *Human Rights and Disability: The Current Use and Future Potential of Human Rights Instruments in the Context of Disability*, eds. G. Quinn and T. Degener (United Nations, 2002), 13, 14.
- Series L (2015). 'Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms' *International Journal of Law and Psychiatry* 40:80–91.

- Shogren KA, Wehmeyer ML, Lassmann H, & Forber-Pratt A (2017). 'Supported Decision-making: A Synthesis of the Literature across Intellectual Disability, Mental Health, and Aging' *Education and Training in Autism and Developmental Disabilities* 52(2):144–157.
- Stainton T (2016). 'Supported decision-making in Canada: principles, policy, and practice' *Research and Practice in Intellectual and Developmental Disabilities* 3(1):1–11.
- Stavert J (2018). 'Paradigm Shift or Paradigm Paralysis? National Mental Health and Capacity Law and Implementing the CRPD in Scotland' *Laws* 7(26).
- Then S-N, Carney T, Bigby C, & Douglas J (2018). 'Supporting decision-making of adults with cognitive disabilities: The role of Law Reform Agencies – Recommendations, rationales and influence' *International Journal of Law and Psychiatry* 61:64–75.
- Watson J (2017) 'Supported Decision-making' *Intellectual Disability Australasia* Dec 2017: 3-5
- Watson J, Wilson E & Hagiliasis, N (2017) 'Supporting end of life decision-making: Case studies of relational closeness in supported decision-making for people with severe or profound intellectual disability' *Journal of Applied Research in Intellectual Disabilities* 30(6):1022-1034.
- Watson J (2016). 'Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability' *Laws* 5(6).
- Watson J, Anderson J, Wilson E, & Anderson KL (2020). 'The impact of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on Victorian guardianship practice' *Disability and Rehabilitation*.
- Werner S, & Chabany R (2015). 'Guardianship Law versus Supported Decision-Making Policies: Perceptions of Persons with Intellectual or Psychiatric Disabilities and Parents' *American Journal of Orthopsychiatry* 86(5).
- Wiesel I, Smith E, Bigby C, Then S-N, Douglas J, & Carney T (2020). 'The temporalities of supported decision-making by people with cognitive disability' *Social & Cultural Geography*.
- Wolpert J (1980). 'The Dignity of Risk' *Transactions of the Institute of British Geographers* 5(4):391–401.

## 7.4 Presentations, conference papers, online resources

- Bigby C, & Douglas J (2020b). Preliminary evaluation of the La Trobe Support for Decision-making Practice Framework (PowerPoint). Available at [https://www.latrobe.edu.au/\\_data/assets/pdf\\_file/0007/1187062/SfDM\\_Bigby\\_Douglas.pdf](https://www.latrobe.edu.au/_data/assets/pdf_file/0007/1187062/SfDM_Bigby_Douglas.pdf).
- Gimson S (2015). Supported Decision-making (The Council on Quality and Leadership, United States) (PowerPoint) Available at [https://dail.vermont.gov/sites/dail/files/documents/Supported\\_Decision\\_Making.pdf](https://dail.vermont.gov/sites/dail/files/documents/Supported_Decision_Making.pdf).
- Hanslow K (2019). From Substitute to Supported Decision-making. Understanding the Changing Landscape of Guardianship Law. Presentation to the RANZCP Faculty of Psychiatry of Old Age 2019 Conference (PowerPoint). Available at <https://www.ranzcp.org/files/resources/conference-presentations/faculty-of-psychiatry-of-old-age/kate-hanslow-from-substitute-to-supported-decision.aspx>.

The La Trobe Support for Decision-making Practice Framework Learning Resource. Available at <https://www.supportfordecisionmakingresource.com.au/>.

United Nations, Office of the High Commissioner for Human Rights (OHCHR) (2014). Training Package on the Convention on the Rights of Persons with Disabilities (Online): [https://www.ohchr.org/EN/Issues/Disability/Pages/TrainingmaterialCRPDConvention\\_OptionalProtocol.aspx](https://www.ohchr.org/EN/Issues/Disability/Pages/TrainingmaterialCRPDConvention_OptionalProtocol.aspx).