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of People with Disability

Research
Report

Diversity, dignity, equity and best practice: a framework for supported decision-making

The Living with Disability
Research Centre, La Trobe University

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Research Team

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Contents

Key to abbreviations

Acronym	Meaning
AAT	Administrative Appeals Tribunal
ABI	Acquired brain injury
ALRC	Australian Law Reform Commission
ALRC Principles	The 4 national decision-making principles recommended in the ALRC Report
ALRC Report	Equality, Capacity and Disability in Commonwealth Laws (ALRC Report 124)
ARC	Australian Research Council
CRPD	Convention on the Rights of Persons with Disabilities
CRPD Committee	United Nations Committee on the Rights of Persons with Disabilities
La Trobe Framework	La Trobe Support for Decision-making Practice Framework
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NSWLRC	New South Wales Law Reform Commission
OPA	Office of the Public Advocate
PAD	Psychiatric Advance Directive
PO	Personal Ombudsman
SDM	Supported decision-making
TAC	Transport Accident Commission (Vic)
The Framework	Diversity, Dignity, Equity and Best Practice: A Framework for Supported Decision-Making [ie, as recommended in this Report]
VCAT	Victorian Civil and Administrative Tribunal
WHO	World Health Organisation

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Executive Summary

Aims

This research aimed to understand the significance of supported decision-making to the lives of people with cognitive disabilities, identify its essential elements common to anyone with cognitive disabilities in any context, and locate key implementation issues. For this Report, we understand people with cognitive disabilities to include people with intellectual disabilities, acquired brain injury, dementia and mental health conditions. Synthesising the research findings, this Report articulates the benefits of supported decision-making, sets out nine principles and eight essential elements of a 'Diversity, Dignity, Equity and Best Practice Framework for Supported Decision-making' and recommends implementation strategies.

Methods

Different methods feature in each part of the study. The full findings from each appear as appendices.

- A rapid focused, narrative review of local and overseas peer-reviewed and grey literature, concentrating on issues central to project aims (Appendix A).
- An online survey of research and practice networks to locate recent initiatives and research in progress (Appendix B).
- Focus groups and individual interviews to build new empirical data, capturing experiences of supported decision-making and opinions about essential elements of a framework from a cross-section of 77 people with cognitive disabilities, family members, representative groups, policy makers and advocates (Appendix C).
- An Australian advisory forum of individuals and representatives of organisations experienced in practice, policy and advocacy around supported decision-making, to test ideas and provide feedback as the research progressed.

Issues of severity and type of cognitive disability are pivotal to debate about supported decision-making. Consequently, the language in this Report at times departs from that of 'high support needs' preferred by the Disability Royal Commission. Children were outside the scope of this Report.

Approaches to supported decision-making

There is no shared understanding of supported decision-making across Australia, so there is no agreed approach or direction for reform.

A binary approach is the most common. This sharply distinguishes between supported and substitute decision-making: either there is supported decision-making where a person is supported to actively participate in making the decision and retains control of it; or there is substitute decision-making when, even with support, a person cannot actively participate in making a decision and a substitute decision is made by others based on the person's perceived 'best interests'. The binary approach excludes people with severe cognitive impairments from supported decision-making.

In contrast, the principled approach to supported decision-making adopted in this Report understands it as a continuum of decision support. It includes a person being supported to make their own decisions as well as decisions made based on a supporter's interpretation of the person's will and preferences. Under the principled approach, supported decision-making can be embedded in most forms of decision support. If a person cannot actively participate or communicate their will and preferences, the supporters' best interpretation of the person's will and preferences is applied ('will and preferences substitute decision-making').

Issues of risk mean that the principled approach to supported decision-making does not extend to all decisions. As a last resort and in very limited circumstances a decision guided by the person's personal and social wellbeing being as well as will and preferences ('personal and social wellbeing substitute decision-making') can be made. This only occurs where a person's stated or interpreted will and preferences involve risk of serious, imminent physical or financial harm with lasting consequences to themselves (including incurring civil or criminal liability), and that person is unable to understand that risk even with support. Under the recommended principled approach, the relevant marker of supported decision-making is that a person's stated or perceived 'will and preferences' remain at the centre of the decision. Thus, supported decision-making does not extend to personal and social wellbeing substitute decision-making which is invoked in rare situations of serious risk to the person.

Diversity of supporters and contexts of supported decision-making

Decision supporters are diverse, and not easily categorised. They include unpaid informal supporters, paid supporters providing decision support as part of other day-to-day or intermittent professional support, and paid supporters with dedicated decision support roles.

People with cognitive disabilities who benefit from supported decision-making are similarly diverse. Their need for support may be lifelong, episodic or acquired during adulthood. The degree and type of support a person needs depends on their disability as well as other characteristics such as culture, context and the type of decision. The need for supported decision-making spans all life domains and occurs at home, in civil society, and across multiple service systems, institutions and jurisdictions. Much supported decision-making occurs informally as part of the everyday support provided by paid or unpaid supporters.

Benefits of supported decision-making

Supported decision-making is a fundamental strategy for putting rights into practice. It is important to safeguarding, empowering and furthering the wellbeing of people with cognitive disabilities. It has benefits beyond the individual by emphasising the importance of social connections and promoting change to social attitudes towards people with disabilities.

Principles of a supported decision-making framework

We propose a ‘Diversity, Dignity, Equity and Best Practice Framework for Supported Decision-Making’ (Framework) to guide all supported decision-making legislation, policy, programs and practice across all jurisdictions, service systems, people with cognitive disabilities, types of decisions and contexts in Australia.

Chapters 1 and 2 discuss the nine universal principles of the Framework. The first four are based on the 2014 report of the Australian Law Reform Commission and the other five emerged from the research for this study. In particular the principles address: the rights of all people to autonomy and to access support to make decisions; the uncertainty about the nature of supported decision-making through the adoption of the principled approach to supported decision-making; the deep inequities that exist in access to resourceful family or other sources of informal support for decision-making through adopting a principle of distributional equity; and the need to bring the perspectives of people with lived experience of cognitive disability as well as experiences of supporters to the fore through their co-leadership and co-design of future supported decision-making initiatives.

Recommendation 1 Nine universal principles should inform the Framework for supported decision-making:

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

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

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

Principle 4: Safeguards. Laws, legal and policy frameworks must contain appropriate and effective safeguards in relation to interventions for people who may require decision-making support, including to prevent abuse and undue influence.

Principle 5: Principled approach to supported decision-making. A principled approach to the concept and practice of supported decision-making should be adopted that keeps an individual's stated or perceived 'will and preferences' at the centre of decision-making. This approach recognises the realities of the practice of providing supported decision-making, particularly for those with severe cognitive disabilities.

Principle 6: Best interpretation of will and preferences. In the very limited circumstances where a supporter has not been able to elicit a person's will and preferences a decision should be based on their best interpretation of what the person's will and preferences would be.

Principle 7: Dignity and risk. The dignity and importance of taking risks is acknowledged and supported. In very limited circumstances, where a person's stated or inferred will and preferences involve risk of serious, imminent physical or financial harm with lasting consequences to themselves (including incurring civil or criminal liability), and that person is unable to understand that risk even with support, personal and social wellbeing substitute decision-making is applied as a last resort with the person's personal and social wellbeing at the centre.

Principle 8: Distributional equity. All supported decision-making reform and initiatives should be premised on the ethical principle of a commitment to distributional equity of access to supported decision-making. Those experiencing disadvantage in access to support for decision-making should be given priority in new programs.

Principle 9: Co-leadership of people with cognitive disabilities. People with cognitive disabilities and supporters of people with severe cognitive disabilities should lead consultation and design processes for supported decision-making reform and initiatives.

Elements of the Framework

The Framework includes eight essential elements as design imperatives for operationalising universal principles and development of supported decision-making law, policy, programs and practice. The rationale for each, and recommendations for implementation are set out in Chapters 3-8.

Recommendation 2 Eight elements be included in the Framework.

- Element 1: Recognising diversity in supported decision-making
- Element 2: Interrelationship of supported decision-making with other systems
- Element 3: Use of best practice and ethical supported decision-making
- Element 4: Capacity building at individual, system and institutional levels
- Element 5: Safeguarding, quality assurance and oversight
- Element 6: Enabling forward planning
- Element 7: Adequate funding
- Element 8: Strategies to build social connections

Element 1: Recognising diversity in supported decision-making (Chapter 3)

People who need support for some or all decisions, differ in terms of type and severity of cognitive impairment, personal attributes and identity such as age, gender, sexuality, cultural background, socioeconomic status and other forms of human diversity. Those differences impact in various ways, including: whether and how cognitive abilities change over time; the extent and nature of social connections; the service systems they engage with; personal histories of living with or without a cognitive disability; cultural expectations relating to autonomy and forms of support; geographical and economic barriers and enablers to accessing formal and informal support.

Different approaches to implementing supported decision-making are needed to account for the diversity of people who benefit from it. Recognising diversity is essential to the Framework in ensuring that universal principles are translated into law reform, policy, programs and best practices appropriate to meeting diverse disability-related support needs, and social and cultural contexts.

The knowledge base about the practice of supported decision-making is very uneven, posing major challenges in designing initiatives for some identity or cultural groups. In particular, there is very little research about supported decision-making with First Nations people, people identifying as LGBTIQ, or people from culturally and linguistically diverse backgrounds.

Recommendation 3 Reform of law, policy and development of initiatives must take account of the diversity of people with cognitive disability, contexts and supporters, decisions, jurisdictions and systems to ensure that universal principles are translated into the types of programs and best practice that are appropriate to meeting diverse disability-related support needs as well as diverse social and cultural contexts.

3.1 Funding priority and specific attention should be given to the design of the suite of measures that aims to further understand how the principles and elements of the supported decision-making framework can be interpreted and applied to culturally and linguistically diverse and First Nations community settings. This should include recognition of informal expressions which expand or refine the intention behind decisions to appoint a supporter or substitute decision-maker and expectations of those supporters.

3.2 It is too early in the development of supported decision-making programs and there is too little evidence about its implementation across diverse groups, sectors and institutional arrangements to be prescriptive about a consistent programmatic type of supported decision-making. There should be continuing room for innovation and for evidence to be gathered about what works, in what contexts, for whom.Nevertheless, all developments should be driven by the application of universal principles of supported decision-making.

Element 2: Interrelationship of supported decision-making with other systems (Chapter4)

People with cognitive disabilities require support with decision-making within and across the boundaries of the multiple jurisdictions, services, institutions and informal spheres of life with which they interact. These have differing values, legislative frameworks and traditions, resulting in considerable inconsistencies in approaches to decision support. Supported decision-making cannot stand alone, rather holistic law, policy and practice reform is required to embed and operationalise it within multiple formal systems and informal civil society arrangements.

There is also potential to reform the best interests substitute decision-making provisions that are entrenched in systems such as guardianship and administration, NDIS and Centrelink nominee provisions, and forward planning legal instruments such as enduring powers of attorney, which impact high numbers of people with cognitive disabilities now and potentially in the future.

Recommendation 4 The interrelationships of supported decision-making with other formal systems and informal spheres of life means that supported decision-making cannot stand alone and must be embedded in and connected to existing systems with different institutional and legislative frameworks.

4.1 Context-specific supported decision-making action plans should be produced for different service systems and institutional settings, each outlining a portfolio of legislative and non-legislative measures to improve quality and take up of supported decision-making in that context, while adhering to a shared agreed set of universal principles.

4.2 All 'unsound mind' provisions in Australian electoral law should be repealed, and strategies put in place to ensure all people with cognitive disabilities are enrolled to vote but not penalised if they choose not to.

4.3 State or Territory laws enabling 'default' substitute decision-makers for healthcare decisions should be reformed so that substitute decisions made by default substitute decision-makers accord with a principled approach, have the will and preferences of the person at the centre, are a last resort and for the shortest possible time.

4.4 State or Territory laws allowing self-appointment of substitute decision-makers with authority to make decisions once a person is no longer able to make decisions should be reformed to reflect a principled approach to supported decision-making and ensure that decisions made by the substitute decision-maker are in accordance with the will and preferences of the person.

4.5 Centrelink payment nominee, correspondence nominee and associated arrangements should be reformed to reflect a principled approach to supported decision-making and ensure that decisions made by the substitute decision-maker are in accordance with the will and preferences of the person.

4.6 NDIS nominee provisions should be reformed to reflect a principled approach to supported decision-making and ensure that decisions made by the substitute decision-maker are in accordance with the will and preferences of the person.

4.7 State and Territory guardianship and administration laws should be reformed in accordance with a principled approach to supported decision-making. New statutory tribunal appointed supporter roles (similar to Victoria) should be implemented but consideration given to the need for a person to consent to tribunal appointed supporters or for decision-making capacity to be restored as a condition of appointment.

4.8 Collection of monitoring data on trends in various types of support, nominee, attorney/guardianship powers should be collated and surveys undertaken to obtain data about informal arrangements. The Australian Institute of Health and Welfare may be an appropriate body to have carriage of this responsibility.

Element 3: Use of best practice and ethical supported decision-making (Chapter 5)

Supported decision-making practice frameworks grounded in evidence are an important guide for supporters, providing reference points for support processes and a form of accountability. The two most cited evidence informed frameworks are the La Trobe Support for Decision-making Practice Framework and the one by the Australian Cognitive Decline Partnership Centre, both of which were endorsed by study participants as good practice. They share similar elements such as knowing the person, identifying the decision, and exploring options and will and preferences before identifying constraints on the decision. These practice frameworks highlight the need for person and context specific knowledge. The most common requirement for supporters is time and self-reflection. The high emotional load and complex task of decision support must be recognised through programs to build supporter capacity. The practice literature about specific groups is uneven, with very little research regarding people with more severe or profound cognitive disabilities, or the impact of formal recognition of supporters on the quality of support.

Recommendation 5 Use of evidence-informed best practice frameworks in supported decision-making should be central to all supported decision-making programs and initiatives

5.1 The following categories be used to distinguish between supporters:

- Informal unpaid civil society supporters (for example, family, friends, associates, volunteers) with no formal recognition as a decision supporter
- Unpaid civil society supporters with a formal appointment as a decision supporter for all or some decisions (for example, a friend appointed as a legally recognised supporter ('supportive attorney') in Victoria)
- Paid supporters who provide supported decision-making as part of their professional or support role and are monitored by their employer, subject to a code of conduct or professional registration requirements (for example, aged care workers or health care professionals)
- Paid supporters who are formally appointed and recognised as decision supporters (for example, a statutory guardian of last resort adopting a principled approach)
- Paid supporters who have a dedicated role in decision support and who may or may not be formally recognised (for example, an employed decision supporter in a funded pilot supported decision-making scheme).

5.2 A national repository of resources for best practice supported decision-making should be established and actively curated to assess the strength of evidence on which they are based and promote dissemination of evidence informed resources. This would serve as a resource for dynamic communities of practice in sharing knowledge and experiences of supported decision-making generally, or for specific groups or sectors.

5.3 Further research is needed on different forms of recognition or legal standing for paid and unpaid supporters, and their impact on the quality of supported decision-making.

5.4 Further research is needed in particular on how supported decision-making can work in the context of people with disabilities with severe cognitive impairments.

Element 4: Capacity building at individual, system and institutional levels (Chapter 6)

Change to the culture of systems and institutions, to community expectations and increased capacity of paid and unpaid supporters are needed to implement supported decision-making. Evidence on best practice supported decision-making should translate into training programs and resources widely disseminated to supporters and through communities of practice. A broad range of strategies, some with targeted audiences and others more generic, could increase the skills of all potential supporters, assist people with disabilities to know their rights to support, maximise effectiveness of support, raise community expectations about involvement of people with disabilities in decision-making, and contribute to cultural change.

Supporting people with cognitive disabilities to understand their rights to support for decision-making and building their capacity to participate in decision-making is also critical to bringing about change. Strategies should reflect the value of peer support and self-advocacy groups in enabling people to exercise their rights and draw on research about developing self-determination from psychology and special education.

Awareness and understanding of supported decision-making – as an element of disability rights more broadly – needs to be promoted across the wider public. This can be achieved through public awareness campaigns, embedding respect for disability rights in the education system; encouraging positive media coverage of disability related issues, and supported decision-making more specifically. The success of such campaigns will depend on inter-sectoral collaboration across different tiers of government, business and civil society organisations, educational institutions and the broader community.

Recommendation 6 Capacity building at the individual, system and institutional level should be a key strategy for implementing all aspects of the Framework.

6.1 A key focus in the design of new supported decision-making programs and initiatives should be capacity building of paid and unpaid supporters.

6.2 There should be a focus on capacity building of people with cognitive disabilities that enables development of their skills in decision-making and / or optimal use of available support for decision-making. This is particularly important across the entire life course for people with intellectual disabilities.

6.3 Particular attention should be given to capacity building initiatives that account for the needs of diverse people, by disability type and severity, and for people from diverse cultural backgrounds and First Nations peoples.

6.4 Awareness of supported decision-making and skills in best practices should be built into the NDIS workforce competence framework and core competencies of all professionals involved in health, aged care, legal, financial, human service and criminal justice systems.

6.5 A proactive approach is needed to disseminate capacity building resources, especially to informal supporters. This should include proactive circulation of information about resources through diverse media and networks, and incentives for supporters to actively engage in capacity building programs.

6.6 To move away from a culture of protection to one that enables people to take on and experience risks, all supporters, organisations and institutions involved with people with cognitive disabilities should have access to education on risk enablement and the positive aspects of risk taking to avoid an overly protective approach to all types of risk.

6.7 To increase awareness, understanding and respect for disability rights, and decision-making rights in particular, there is a need for public awareness campaigns and embedding content on disability rights in the education system.

Element 5: Safeguarding, quality assurance and oversight (Chapter 7)

Supported decision-making often happens in private spaces and in relationships of unequal power. This creates risk of manipulation, undue influence and abuse by supporters. Safeguards, quality assurance and oversight are integral elements of a supported decision-making framework. Different forms of oversight are needed for different contexts and supporters. Safeguarding can be implemented through standards and accreditation of services and their workers in the NDIS and aged care sectors and through professional registration and codes of conduct for allied health, medical, legal and financial professionals in a broad range of service systems. Practices such as formal documentation of supported decision-making processes, and scrutiny by third parties, may assist in monitoring the quality of support but these are resource intensive, and not equally effective in all settings.

Education, capacity building and incentives are more appropriate approaches for oversight and quality assurance for unpaid supporters. Informal monitoring can be achieved by having more than one supporter, providing 'multiple eyes' to look out for a person. Suspected abuse by supporters can be handled by existing processes, including those under offices of the Public Guardian or Public Advocates. Where unpaid supporters have some formal standing, their duties can be legislated, and tools like supported decision-making agreements may clarify expectations.

Recommendation 7 Approaches to safeguarding, quality assurance and oversight should use strategies that best meet the needs of the different contexts in which supported decision-making occurs and are proportionate to risk.

7.1 Existing disability rights advocacy organisations and decision support infrastructure – such as offices of Public Advocates, Public Guardians and tribunals – should be appropriately funded and used to deliver education, guidance and oversight of supported decision-making practice.

7.2 Different approaches to safeguarding and monitoring are required for the different types of supporters.

7.3 Education, training and financial incentives – rather than external regulatory monitoring, 'codes of conduct' or punitive measures – should be applied to improve the quality of supported decision-making by unpaid supporters.

7.4 For formal supporters a range of measures are needed such as service and professional codes of conduct, standards or accreditation about supported decision-making.

Element 6: Enabling forward planning (Chapter 8)

Forward planning enables people to make their own arrangements for future needs for additional decision support. Existing legal instruments are nearly always about substitute decision-making. They are familiar to legal, health and aged care professionals, and often valued for reasons of convenience or protection from risk. There is potential to reform and expand these instruments to align with a principled approach to supported decision-making. A challenge with all forward planning is that will and preferences can change over time in a way that a person cannot always predict or plan for. Innovative measures are required to raise understanding among legal, health and aged care professionals about the broader benefits of embedding supported decision-making in forward planning discussions.

Recommendation 8 All Australian legal instruments for forward planning should reflect a principled approach to supported decision-making by being directed by will and preferences, including that when a person with cognitive disability receives supported decision-making from an informal or formally appointed decision supporter enabling them to make clear their advance wishes, these wishes should be respected.

8.1 State and Territory laws should be reformed to offer the option for people to self-appoint a legally recognised supporter for decision-making (as in Victoria). However, consideration should be given to setting the lowest possible level of understanding needed for such appointments and to providing the option of appointing enduring supporters.

8.2 Create and widely disseminate ‘templates’ for forward planning that align with principles of supported decision-making and allow for recording statements of will and preferences.

8.3 Develop and deliver education programs – both for the public at large, and targeted at legal and medical professionals, disability and aged care support workforce – about the benefits and best practice for supported decision-making through forward planning.

8.4 Give particular attention to adapting forward planning legal instruments, templates and education for the needs of diverse people, by disability type and severity, and for people from diverse cultural backgrounds and First Nations people.

Element 7: Adequate funding (Chapter 8)

Significant resources are required to implement supported decision-making. This is particularly the case given the multiple systems where change and capacity building are required, the significant proportion of people without resourceful family or other unpaid supporters, the need for safeguarding and strategies for developing social connections for isolated people. Significant harm is likely if laws or programs are abolished that deny agency and autonomy – such as guardianship and other substitute decision-making – without adequate resources to implement all elements of the Framework.

While paid dedicated decision supporters are an appropriate option of last resort for isolated people, funding should be separate from resourcing needed to promote supported decision-making in general. Any new 'industry' delivering paid dedicated decision support should be avoided.

Recommendation 9 Provision of adequate funding is needed to enable supported decision-making to be implemented within and across sectors and jurisdictions in Australia. This bespoke national funding should be separate from and additional to, reliance on funding from service packages in Commonwealth, State or Territory schemes such as the NDIS, Aged Care, and other individualised funding packages for support for people with cognitive disabilities.

9.1 A comprehensive cost-benefit analysis, accounting for the full cost of implementing a full package of supported decision-making programs, against an assessment of the benefits to society should be undertaken which should also map which levels and branches of government will bear which costs.

9.2 NDIS, aged care and other State or Territory schemes for individualised packages of funding for support for people with cognitive disabilities should fund supported decision-making for participants who have no access to informal sources of support.

Element 8: Strategies to build social connections (Chapter 8)

Many people with cognitive disability are socially isolated and have no access to any unpaid supporters. For them, supported decision-making depends on the availability of paid supporters who are likely to be their primary service providers. For this group, effective supported decision-making depends on formal support to build informal social connections. However, common strategies such as circles of support and microboards rely on a person already having a core supporter around whom a network could be generated. There is a significant gap in evidence about costs and strategies for building and maintaining social connections for people without existing family or informal core supporters.

Recommendation 10 Strategies to build social connections of people with cognitive disabilities who are socially isolated should be a priority investment in supported decision-making programs and initiatives.

10.1 A comprehensive research program to understand how to build social connections for people with cognitive disabilities who do not have existing strong family or informal relationships should be funded as a priority.

10.2 Demonstration programs to build lasting and robust social networks of people with cognitive disabilities who are socially isolated should be funded and evaluated as a priority.

Developing approaches to co-leadership and co-design

People with cognitive disabilities and supporters of people with severe cognitive disabilities should lead consultation and design processes for supported decision-making reform and initiatives. Although good public policy rests on co-design there is much to be learned about effective co-design strategies with people with cognitive disabilities and especially how to include perspectives of those with more severe and profound impairments.

Recommendation 11 People with cognitive disabilities and supporters of people with severe cognitive disabilities should lead consultation and design processes for supported decision-making reform and initiatives.

11.1 Further research is needed to ensure people with more severe or profound cognitive disabilities are not excluded from co-leadership and co-design efforts. This extends to research about the practices of inclusion of people with cognitive disabilities in advisory and co-design initiatives to understand how processes should be adapted to create inclusive environments and the types of skills and strategies required to provide effective tailored support to individuals to enable their participation.

11.2 The principles and elements of the Framework were derived through a process that involved extensive consultation with people with cognitive disability, advocates as well as professionals. However, this Framework should be debated, and refined further if necessary, in a process that involves co-leadership of people with disability and supporters of people with severe cognitive impairments. A reform agenda taskforce co-led by people with disability, including disabled people’s organisations, the Offices of Public Advocates and Public Guardians, carer organisations, disability service providers, NDIS, State, Territory and Commonwealth Government disability ministries should be established for this purpose.

Conclusions

The Framework set out in this Report proposes the universal principles and essential elements to guide the implementation of supported decision-making legislation, policy, programs and practice across all jurisdictions, service systems, people with cognitive disabilities, types of decisions and contexts in Australia. The reform agenda needs to be both comprehensive and measured, recognising that law reform will play only a small part in shifting societal, professional and institutional cultures to view supported decision-making as the norm, rather than the exception. Reforms to embed supported decision-making must be centred around co-leadership and co-design with people with cognitive disability and their decision supporters, and engage all levels of government, non-government agencies, and civil society.

Chapter 1. Introduction

1.1 The project brief

This research was commissioned to inform the work of the Disability Royal Commission on the development and implementation of frameworks for supported decision-making in Australia and to make recommendations to give effect to Australia's obligations under the Convention on Rights of Persons with Disabilities (CRPD).[1] Article 12 of the CRPD articulates the right of persons with disabilities to enjoy legal capacity on an equal basis with others in all aspects of life and also holds signatory nations responsible for developing appropriate measures to provide access to persons with disabilities to the support they may require in exercising legal capacity.

The study aims to: understand the significance of supported decision-making to the lives of people with cognitive disabilities; identify the essential elements of supported decision-making frameworks common to all people with cognitive disabilities and contexts in Australia and identify issues key to implementing supported decision-making and practice in Australia including differences between groups and contexts. Supported decision-making among children was outside the scope of this Report.

The research questions posed by the Disability Royal Commission were:

Elements of supported decision-making frameworks

1. What does supported decision-making mean and look like in practice for people with disability? How does supported decision-making reduce the risk of violence, abuse, neglect and exploitation for people with disability in different contexts?
2. What are good practice or innovative approaches to supported decision-making in Australia and comparative jurisdictions? How have these been assessed or evaluated? What underlying assumptions inform these different approaches?
3. Are there essential or key elements that should inform supported decision-making frameworks for people with disability in Australia? Do these key elements differ according to the context (eg, NDIS vs guardianship) and the nature of impairment (eg, people with high support needs)?

Putting supported decision-making frameworks into practice

4. How should the role of families, carers and supporters (including legal entities such as microboards) be recognised in supported decision-making frameworks? For example: Is it necessary to distinguish between support provided by family and friends, carers and support provided by paid professionals? Should quality assurance and accreditation standards be applied to advocacy or other organisations providing professional support, but not for support arrangements involving family or friends?
5. What are the potential risks and impacts of a statutory supported decision-making framework on informal supported decision-making arrangements?

6. What safeguards, monitoring and oversight mechanisms need to be in-place for a supported decision-making framework?
7. Are there gaps in evidence and practice that could be informed by future research?
8. What barriers — legislative or otherwise — exist in implementing supported decision-making frameworks in Australia? What could be done to address these?

1.2 Methods

The research used mixed methods which comprised:

Literature review: A rapid focussed narrative review of the Australian and international peer-reviewed and grey literature concentrated on aspects central to project aims.[2] Social science databases searched included PsycInfo, CINAHL, Embase and Medline, legal databases were also searched and hand searches conducted. Material published between 2011 to Sept 2021 was included with a final count of 322 items. The comprehensive review and more details on methods is published as Appendix A to this Report.[3]

Brief online survey: A brief online survey, distributed to research and practice networks, aimed to capture recent initiatives, research work currently in progress or reports of projects on supported decision-making but not yet dealt with in the published literature due to publication time lags. The Report of this survey is published as Appendix B to this Report.

New empirical data: Focus groups and individual interviews conducted with 77 people collected data from a cross-section of people with cognitive disabilities, representative groups and other stakeholders on essential elements of supported decision-making frameworks and their implementation. To capture the diversity of people with cognitive disabilities and stakeholders interested in supported decision-making, and identify shared as well as group specific issues, the focus group sample included disability or sector specific groups as well those that represented broader constituencies. An analysis of the main themes in these data provided the lens and structure of this Report and is published in full as Appendix C.[4]

Advisory group: A stakeholder group of Australian individuals and representatives of organisations experienced in practice, policy and advocacy around supported decision-making provided a forum for the research team to test ideas and gain feedback on work in progress.

This Report synthesises key findings relevant to the questions posed by the Disability Royal Commission, drawing on data from the different parts of the study. The recommendations are addressed both to the Disability Royal Commission in its immediate work but also to the wider audience of those developing and implementing supported decision-making into the future. This Report was informed by feedback from the Advisory Group on the issues emerging from the data analysis and two days of discussion about supported decision-making and guardianship convened by the Disability Royal Commission in late May which were attended by two members of the research team.

The process of commissioning the Report and the necessarily tight time frame for its completion meant it was not feasible for the project to be co-led by representatives of the four main groups of people with cognitive disability who are its primary focus (people with acquired brain injury, mental health conditions, intellectual disabilities or dementia). We acknowledge this is a limitation of the study, especially considering our recommendation that reforms that promote supported decision-making should be co-led by people with cognitive disabilities and supporters of those with severe cognitive impairment. We note however that the views of people with cognitive disabilities were canvassed through their participation in focus groups or interviews, and the participation of representatives from key advocacy and peak bodies that seek to represent issues relevant to people with cognitive disabilities.

Through this Report we have referred to specific groups of people with cognitive disabilities to ensure the differences and similarities between the large and diverse group included under this umbrella term could be brought to the fore. We have also referred, at times, to the 'severity' of cognitive disability, departing from the Disability Royal Commission's preferred language of 'high support needs'. The language of high support needs is too generic and overly inclusive for the purpose of this Report. While it may be the case that most people with cognitive disability have high support needs, not all people with high support needs have cognitive disability. Also, severity of cognitive impairment is central to debates about supported decision-making and replacing severity with more generic terminology such as 'high support needs' risks losing the nuances of the arguments being made.

This Report articulates the significance of supported decision-making, sets out principles and essential elements of a 'Diversity, Dignity, Equity and Best Practice Framework for Supported Decision-making' including necessary safeguards. Finally, it identifies barriers to implementation and proposes strategies for implementing best practice supported decision-making in Australia.

1.3 Different understandings of supported decision-making

The term 'supported decision-making' is understood differently by different disciplines, professions and sectors. Supported decision-making is often used as an umbrella term for a wide range of practices that either attempt to recognise and respect a person's wishes (their 'will and preferences') or to comply generally with the CRPD.[5] Differing conceptions, even among the stakeholders in our research, speak to a worrying lack of common understanding of supported decision-making that is likely to extend to the public. As one respondent said,

> [there is a] lack of clarity about difference between substitute decision-making and supported decision-making. A lack of consistency with supported decision-making even in Australia between state legislation. (Advocate-aged care)

While a common understanding of the term is critical, there is also a need to accommodate legitimate variation across sectors without compromising the quality of support. Making explicit the different approaches to supported decision-making is important to facilitate dialogue, explicate the approaches adopted in law, policy and practice, and help to progress practical change across sectors. We identified two main conceptions of supported decision-making from the literature and empirical work, which we discuss in the following sections.

1.3.1 The binary approach: supported decision-making as the opposite to substitute decision-making

Supported decision-making is commonly conceptualised as the binary opposite of substitute decision-making. This binary understanding is grounded to some extent in the CRPD, which framed supported decision-making as a right, and substitute decision-making – and associated institutions such as guardianship – as the wrong approach that should be repealed. From this perspective supported decision-making means the person retains control of their decision, actively participates in making it and is supported to do so. In our fieldwork, this perspective resonated with self-advocate respondents who talked from their own experiences.

> Supported decision-making means you're in control of your decisions but still getting support while doing it. (Self-advocate)

This is very much a common-sense or normative interpretation of supported decision-making, where support assists the person to understand and explore information, options and the implications of decisions, and the person clearly makes the decision themselves.

Respondents found it particularly difficult to apply this way of thinking to people with more severe cognitive impairments, as even with support they would be unlikely to understand the choices or implications of most decisions or make many decisions themselves.

> Some people will always need a substitute decision made – to pretend that a substitute is a supporter could lead to abuse. (Advocate–disability)

> For someone who has a profound cognitive disability – is the supporter making substitute decisions in essence? I think they probably would be, in which case, we would need to recognise them as a substitute decision-maker, not as a supporter. (Advocate-generic)

> ...when do you need to take over when someone clearly has not got capacity at that point. This needs to be part of practice/program design. (Advocate–disability)

As the quotes illustrate, implicitly the binary conceptualisation of supported decision-making is underpinned by ideas about capacity. The purpose of supported decision-making and the role of supporters are to extend the decision-making autonomy (and capacity) of a person to the maximum extent possible. When a person is perceived to lack sufficient decision-making capacity for a particular decision, even with access to support, then substitute decision-makers rather than supporters become necessary.

This accords with the conceptualisation of supported decision-making that has been reflected in some Australian laws[6] and is largely how most Law Reform Commissions envisage changes to the law.[7] Thus, law reform has seen supported decision-making as an adjunct to substitute decision-making, as something that should be attempted before substitute decision-making and, in legal contexts, before removal of decision-making rights.[8]

Understood in this way, a person must be able to reach a threshold of decision-making capacity (including with any support) for supported decision-making to apply. If a threshold of capacity, relevant to that decision, cannot be reached even with support, then supported decision-making no longer applies and substitute decision-making becomes necessary.

However, where that threshold is set and the line around supported decision-making drawn in practice, is by no means clear. Respondents drew attention to the complexities involved, asserting that the line would differ not only for each person but also for each decision in which a person might be involved and their circumstances at that time.

> …need to assess level of support they require to make that decision. Depends on the nature and complexity of the decision. (Advocate–carer)

> …someone living with dementia their cognition, and their other needs, will change over time, and so the supported decision-making process will necessarily change along with that, and it may well be, at the end, that supported decision-making is not possible…When is it not possible? Million-dollar question – no clear answer. (Advocate–aged care)

While this binary conceptualisation of supported versus substitute decision-making is a common way of viewing supported decision-making, there are problems in accommodating all people with cognitive disabilities within this approach.

1.3.2 Challenges in including people with severe cognitive disabilities in a binary conception of supported decision-making

Both the literature and respondents considered the binary conceptualisation of supported decision-making as particularly ill-suited to those with the most severe cognitive impairments. People in this group may have very limited ability to understand decisions, options or risks, which means supporters must rely on their knowledge of the person, or their behaviours or demeanour, in order to interpret their preferences. This is, however, a diverse group of people, as severe cognitive impairment manifests in different ways. For example, people with profound intellectual disability may not use words or concepts to communicate, whereas those with dementia or severe acquired brain injury (‘ABI’) may find it difficult to retain new information, consider alternatives, generate ideas or hold back impulsive responses. All disability groups include people with severe cognitive impairments who are often referred to as ‘hard cases’, for whom a binary approach to supported decision-making would not apply, and substitute decision-making would be seen as the only alternative.

The Committee on the Rights of Persons with Disabilities (‘CRPD Committee’) is the UN body responsible for monitoring implementation of the CRPD. It has stated that where it is not possible to determine a person’s will and preference, a ‘best interpretation’ of their will and preference should be adopted.[9] However, the binary approach demands active participation by a person in decision-making and does not extend to the idea of supporters interpreting a person’s will and preferences. Partly this is because the literature identifies it as particularly challenging to rely on supporters’ interpretations of behaviour or demeanour to determine the will and preferences of people with severe cognitive impairments.[10] It also points to the issues associated with the accountability of supporters using this ‘best interpretation’ method and potential threats to safety of people with severe cognitive.[11] As Keeling points out[12] and the empirical evidence demonstrates, there are both ‘good’ and ‘bad’ relationships of support.

Respondents in our research felt strongly that people with severe cognitive impairment had largely been left out of conversations about how supported decision-making applied to them. They felt that they should not be excluded from the benefits of supported decision-making, and some endorsed ideas of best interpretation despite the challenges.

> The hard one is profound disability, particularly where that is something that the person has been born with – I guess that ability to demonstrate preference, for instance, probably only comes through in a behavioural sense as opposed to verbalising decision-making preferences and I think that then becomes a really challenging process… but there are always ways of eliciting a preference using alternative communication methods. Yes, sometimes those are and will always be indicative decisions using action or behaviour versus verbalisation… But that’s not to say that there aren’t other areas of decision-making that they can and clearly do indicate preference in. (Advocate–generic)

Some respondents considered that interpreting the preferences of a person with severe cognitive impairment did not naturally fit within the binary understanding of supported decision-making, suggesting alternative approaches are necessary.

> And it’s almost like there does need to be another name for that space. It’s not quite substitute, it’s not supported. There’s something else there, I don’t know what you’d call it. (Advocate–generic)

> I certainly see a role for some form of decision-making for persons whose will and preferences is not clear. And I’m not going to call that 100% support for them to exercise their will because I just see that as a sort of fantasy stretched too far. … I’ve often distinguished between supported decision-making and then a different category that would be described as either facilitated decision-making or representational decision-making. (Family–disability)

> …maybe there needs to be another term there because it’s not substitute decision-making in that sense of, “This person cannot make a decision and so someone else is just going to need to do it in this circumstance.” And it’s also not “Here is their decision because I understand [their preferences] that I’m just telling you what it is.” There is something in the middle there where you are really trying to make a decision that’s really honouring the person’s participation and really trying to identify their wishes even when that’s incredibly difficult but acknowledging that there’s a whole heap of interpretation going on there, so you can’t be sure that that is what the person wants. (Advocate–disability)

Despite the challenges identified, little attention has been given to research or law reform on supported decision-making for people with severe cognitive impairments.[13] However, the evidence there is on how decision-making occurs in practice with this group, indicates that support and substitution are not viewed in opposition, but rather as existing along a spectrum.

This view is particularly the case in the everyday context more broadly where both unpaid and paid supporters often move between providing support and making substitute decisions depending on the context and decision to be made.[14] This perspective demands a different conceptualisation of supported decision-making from a binary approach, one that does not draw a sharp distinction between supported and substitute decision-making.

1.3.3 Supported decision-making as a principled approach to decision-making

This second perspective conceptualises supported decision-making as a principled approach to decision-making which applies to all people irrespective of whether a person actively participates in making a decision or it is made by a supporter based on interpretation of the person's will and preferences. From this perspective the principles of supported decision-making should be embedded in any form of decision support. Therefore, all forms of decision-making on behalf of the person with a cognitive disability, in all settings, should take account of the person's will and preferences. This perspective was asserted by many of our respondents,

> …so that supported decision-making is practised even when there is a guardian. (Advocate–carer)

> …there should be an increasing legal requirement for people making substitute [or representative] decisions on a 'substitute judgment' basis… means that the representative makes decisions that accord with the preferences of the individual. They would still be substitute decisions, but they'd be made by people informed about what the preferences of the person are or were likely to be. (Advocate–generic)

This perspective recognises that the practice of supported decision-making is not necessarily incompatible with relationships where a substitute decision may be made. In practice, support and substitution are on a spectrum where some – but not all – substitute decisions are considered a form of supported decision-making, rather than being in opposition to it.[15] In practice, the relevant marker of supported decision-making is that an individual's stated or perceived 'will and preferences' remain at the centre of the decision.

When a supporter makes a substitute decision based on a person's will and preferences, the literature refers to this as 'substituted judgment'. This approach is recognised as being at one end of a spectrum of supported decision-making. Therefore, even in cases where a decision is legally attributed to another person, the individual's will and preferences remain central and are reflected in the supporter's ultimate decision.

There is an important difference between a substituted judgement approach that falls at one end of the supported decision-making spectrum, and a 'best interests' approach where the substitute is guided by their perception of the individual's 'best interests'. Substitute decision-making guided by 'best interests' is paternalistic and would not be consistent with a principled approach to supported decision-making nor with article 12 of the CRPD.

The principled approach to supported decision-making does not extend to all decisions, as risk of serious harm combined with a person's limited cognitive capacity to understand that risk may mean supporters do prioritise other rights (such as 'personal and social wellbeing') over the person's stated will and preferences. We discuss such exceptional situations where this might occur in the following Section 1.4 on risk.

While we recognise that legal reform has adopted aspects of the binary conception, we propose a principled approach as the preferred and more inclusive way of conceptualising supported decision-making. A principled approach accommodates people with the most severe cognitive impairments and includes them within frameworks of supported decision-making. It also recognises the reality that supported decision-making will inevitably at times encompass another person making a decision on behalf of a person with a cognitive disability (which in the binary approach is termed substitute decision-making). Using the principled approach, in the very limited circumstances where a supporter has not been able to elicit a person's will and preferences, a decision should be based on their best interpretation of what the person's will and preferences would be. However, such decision-making, which we term 'will and preference substitute decision-making' should only be considered a legitimate part of supported decision-making, and in line with CRPD principles when an individual's stated or perceived 'will and preferences' remain at the centre and guide decision-making.

It is important to distinguish between 'substitute' decision-making governed by a will and preference approach that can be considered as part of supported decision-making and that which is based on best interests and thus not consistent with the principled approach. We therefore suggest the following to be incorporated into our recommended principles in Chapter 2.

- **Principled approach to supported decision-making** – A principled approach to the concept and practice of supported decision-making should be adopted that keeps an individual's stated or perceived 'will and preferences' at the centre of decision-making. This approach recognises the realities of the practice of providing decision support, particularly for those with severe cognitive disabilities.[16]
- **Best interpretation of will and preferences** – In the very limited circumstances where a supporter has not been able to elicit a person's will and preferences a decision should be based on the supporter's best interpretation of what the person's will and preferences would be.[17]

1.4 Risk and the limits of supported decision-making in practice

While supported decision-making is a goal that ought to be pursued, it is important to understand its limits and the challenges faced by those who act as supporters. Supporters, whether informal or formally recognised, face similar as well as unique issues whether they are unpaid family, friends or associates, or paid and provide support as direct support staff, managers or professionals.

One significant factor identified in the literature is the impact on supporters' willingness to enable supported decision-making when there is high risk of harm if a person's wishes are respected. Research has found that supporters are often motivated to move into the type of substitute decision-making that overrides will and preferences, when they are concerned that enacting the will and preference of the person will result in some imminent or future harm to the person.[18] This is particularly evident in some service system contexts discussed in Chapter 2 (eg, residential aged care facilities, supported accommodation etc).

Research about the practice of supported decision-making also suggests that supporters draw on the distinction between will (as long-term life directions) and preferences (as a person's more immediate wishes) – as a way of considering issues of risk. When a person's immediate preferences are not well aligned with their will, and may put long term goals at risk, supporters may prioritise will over preferences to avoid risk of long-term harm.[19] This strategy is often invoked in decision-making for healthcare treatment, financial decisions or dietary choices, where immediate preferences may jeopardise longer term goals of independence. These issues illustrate some of the complex judgements that infuse supported decision-making practice and the often imperceptible shift from supported to best interests substitute decision-making.

Most respondents in our research identified the need to retain a form of substitute decision-making which entailed overriding a person's preferences to manage risks of harm to the person themselves. In these cases, for a person with cognitive impairment it is the risk of harm rather than the person's ability or inability to understand the decision that drives the practice of overriding the person's will and preference. Foregrounding risk, in this context, can be understood as prioritising a person's 'best interests' rather than their 'will and preferences'. As one respondent explained,

> I think about supported decision-making, as a recognised right for the person with impaired decision-making capacity, to express their will and preferences, and have them upheld, unless there's some serious safeguarding or care and protection issue that overrides that. (Professional)

Disability scholarship has often been critical of restrictive 'safeguarding' practices in their various forms,[20] particularly best interests substitute decision-making that compromise self-determination by aiming to reduce risks.[21] Much of this work draws on Perske's concept of the 'dignity of risk', which recognises risk-taking can be an act of self-determination and 'healthy development', whereas over-protection and risk avoidance can keep people with disability from 'becoming all they could become'.[22]

In 2014 the Australian Law Reform Commission ('ALRC') published a report titled Equality, Capacity and Disability in Commonwealth Laws ('ALRC Report'). The ALRC saw the dignity of risk and the right of individuals to be empowered to make decisions (even 'bad' ones) as inherent to supported decision-making.[23] However, in recognising that risks of harm are possible, the ALRC proposed that supporters may override a person's will and preferences only where necessary to prevent harm.[24] The ALRC also recommended 'Will, preferences and rights guidelines', proposing that in reaching a decision supporters take account of a person's potentially competing rights as well as their will and preferences. This position is justified by arguing that liberal philosophy and human rights do not necessarily privilege autonomy over all other rights. For example, a supporter may have to weigh an adult's rights to protection of physical and mental integrity in article 17 of the CRPD against their rights to autonomy in article 12. Other relevant rights could include protection from exploitation, violence and abuse (article 16) and ensuring access to health services (article 25).

One of the focus group respondents raised a concern about the ALRC's inclusion of 'rights' in the combination 'will, preferences and rights' as a guide to decision support, saying

> …they go through that series of possibilities, supported decision-making through to where there's substitute decision-making, and a person's well-known preferences should guide the substitute decision-maker. And where there's little to draw from their past, then the substitute decision-maker should act in a way that promotes the person's rights...the use of rights there is problematic, and not particularly instructive, because it doesn't actually help at all, because you can have competing rights to different things…. (Advocate–generic)

The New South Wales Law Reform Commission ('NSWLRC') made recommendations similar to the ALRC about decisions involving risk but (reflecting perhaps the concern raised by this respondent), did not use the term 'rights' recommending that,

> If giving effect to a person's will and preferences creates an unacceptable risk to the person (including the risk of criminal or civil liability), [a substitute decision-maker can be authorised] to make decisions that promote the person's personal and social wellbeing.[25]

The intent of the NSWLRC was similar to that of the ALRC but the NSWLRC referred to substitute decision-makers taking account of a person's will and preferences and 'personal and social wellbeing' rather than will and preferences and rights. The NSWLRC argued that its recommended principles move away from a paternalistic best interests model; accord with the person's right to be 'free from neglect, abuse and exploitation'; and that in ensuring the person is not subject to civil or criminal sanctions, also protect others from harm.

For a minority of decisions, the severity of potential harm may justify allowing other rights of the person to prevail over their current will and preferences, if the person lacks the ability to understand the risks even with support. Distinctions can be made between different levels of risk, and there is room for debate as to what threshold of risk might justify overriding a person's expressed preferences and what processes should be in place to do so. While recognising the complexity of this issue, we suggest that where perceptions of risk consistently lead to substitute decision-making guided by a substitute's view of 'best interests' rather than an individual's 'will and preference', that form of substitute decision-making is not consistent with a principled approach to supported decision-making.

Various approaches should be considered in dealing with the barrier to supported decision-making created by supporters' or service providers' perceptions of risk.

First, capacity building and educative strategies might assist supporters to reframe their approach to risk, from avoidance to risk enablement. The aim would be to equip supporters with strategies to move from a paternalistic protectionist framing of risk dominated by risk avoidance to one more attuned to enabling risk and finding ways to remain true to a person's preferences while minimising the impact of any harm should it eventuate.[26] Capacity building strategies for supporters are outlined further in Chapter 6.

Another approach is to rely on some form of forward planning where a person's enduring will and preferences have been made known to others previously. This approach could be of use where risk of serious harm may arise in a crisis if a person's immediate preferences are respected. This is particularly relevant where a person's preferences change over time or where the severity of cognitive impairment fluctuates over time. For example, use of an advance directive means a person's will and preferences do not become obsolete. A preference expressed during a mental health crisis period may be outweighed by a previous enduring expression of will and preference made at an earlier time when the person is not cognitively impaired. This approach often forms the basis of justifying some involuntary interventions for people with mental health conditions who, for example in the Queensland context,[27] may have a Psychiatric Advance Directive ('PAD') expressing prior wishes for particular treatment or have informed a supporter of their wishes for treatment, even when they refuse at the time.

It is also possible, as already suggested, that current expressed wishes may not be consistent with longer term goals that the person values. In this case overriding a person's immediate wishes may still respect the will of the person. While these assessments of past and future preferences versus current wishes are difficult, and have been acknowledged in the literature,[28] we must recognise the reality that determining a person's will and preference is seldom straightforward for supporters.[29]

The ALRC and NSWLRC both recognised that risk of harm could allow the other rights of a person or their personal and social wellbeing to prevail over their will and preference. However, we suggest that the threshold should be set very high and only exceptional circumstances should justify substitute decision-making, which ought to be guided by a person's personal and social wellbeing as well as will and preferences ('personal and social wellbeing substitute decision-making'). A substitute decision centred on a person's personal and social wellbeing should only ever be made where acting on a person's stated or inferred will and preferences involves risk of serious, imminent physical or financial harm with lasting consequences to themselves (including incurring civil or criminal liability),[30] and that person is not able to understand that risk even with support.[31]

This threshold allows a person's circumstances to be considered for each decision. For example, most decisions about what to eat where a person selects their own diet will not reach the threshold of risk outlined above. However, if a person was diabetic or had other medical conditions and their wish to eat particular foods would lead to risk of serious physical harm with lasting consequences and they did not understand the implications of having that food, then this would allow a substitute decision for some decisions about foods chosen. That substitute decision would be guided by the person's personal and social wellbeing, as well as will and preferences and would enable the person's other rights to prevail. (However, a range of foods which pose less risk should still be offered to make substitute decision-making a last resort.) Such weighing of a person's preferences against risks of serious harm would also necessarily be context specific. While it may be justified to give weight to the risk of harm in the case described, if the same person were in the end stage of a terminal disease there is arguably a greater risk of harm associated with overriding their preferences where they are strongly held, and relatively less gain associated with reducing the risk of serious physical harm.[32]

Another example may be to impose a personal and social wellbeing substitute decision where a person wishes to drive a car but is not licensed and does not have the skills to do so. To allow someone to attempt to drive in those circumstances poses a serious risk of physical harm – to themselves – and the risk of incurring civil or criminal liability. A substitute decision can override their wish to drive unlicensed. (However, steps could be taken to investigate whether the person could be supported to gain their drivers licence in the future.) As determinations of risk will always be dependent on the context and the circumstances of the individual, these examples are not intended to be prescriptive.

The individual making the personal and social wellbeing substitute decision on behalf of the person should ideally be someone who knows that person well and can bring their knowledge of the person, their interests, values and wishes into making the decision. In circumstances where the serious risk threshold is reached, we suggest that best practice should be developed to educate those making such substitute decisions to adopt practices that enable discussion, reflection and revisiting of these decisions. Particularly where supporters may provide supported decision-making as part of their professional role, good, reflective, professional practice should encompass measures such as documentation, justification of reasons, peer discussion and revisiting of such decisions. Best practice is discussed further in Chapter 5.

Similar to the recommended approach of the ALRC and NSWLRC and the current Victorian legislation,[33] personal and social wellbeing substitute decision-making should be considered a last resort. All decision-making processes must start by trying to respect the adult's will and preferences.

Key concepts and factors in our distinction between the binary and principled approaches to supported decision-making are summarised in Table 1.

Table 1. The binary and principled approaches to supported decision-making

Binary approach	Principled approach
EITHER supported decision-making: The person retains control of their decision, actively participates in making it and is supported to do so. The person is supported to make decisions that reflect their will and preferences. Decisions are based on a person's stated will and preferences, not supporters' 'best interpretation' of will and preferences. **OR substitute decision-making:** If a person is deemed lacking capacity to make a decision and communicate their will and preferences, then supported decision-making no longer applies and substitute decision-making becomes necessary based on the person's 'best interests'.	**A CONTINUUM of decision-making supports (including some forms of substitution):** The person is supported to maximise their autonomy in making decisions. Decisions are based on a person's stated will and preferences. Where a person cannot communicate their will and preferences, supporters' best interpretation of the person's will and preferences is applied ('will and preferences substitute decision-making'). The dignity and importance of taking risk is acknowledged and supported. In very limited circumstances, where a person's stated or inferred will and preferences involve risk of serious, imminent physical or financial harm with lasting consequences to themselves (including incurring civil or criminal liability), and that person is unable to understand that risk even with support, a substitute decision can be made as a last resort with the person's personal and social wellbeing being, as well as will and preferences, guiding decision-making ('personal and social wellbeing substitute decision-making').

Consistent with the proposed principled approach to supported decision-making we suggest the following, which is included in our recommended principles of a supported decision-making framework discussed in Chapter 2.

- **Dignity and risk** – The dignity and importance of taking risk is acknowledged and supported. In very limited circumstances, where a person's stated or inferred will and preferences involve risk of serious, imminent physical or financial harm with lasting consequences to themselves (including incurring civil or criminal liability), and that person is unable to understand that risk even with support, a substitute decision can be made as a last resort with the person's personal and social wellbeing, as well as will and preferences, guiding decision-making.[34]

1.5 Benefits of supported decision-making

Despite practical challenges, the evidence from supported decision-making pilots around the world demonstrates its overall benefits. Common outcomes of supported decision-making for people with cognitive disabilities were: increased self-confidence and improved decision-making and self-advocacy skills, and for a few, removal or avoidance of guardianship or administration orders.[35] In one pilot, parent supporters noticed positive changes in their son's or daughter's increased confidence to express preferences and to participate in decision-making.[36] For adults with ABI, supported-decision-making has helped adults to develop a positive sense of self,[37] and for adults with dementia, research shows how being central to decision-making helps them to feel productive[38] and to have a sense of belonging.[39] Our respondents similarly endorsed the beneficial impact of supported decision-making for people with cognitive disabilities.

There was overwhelming support for the concept of supported decision-making from the focus group respondents and stakeholders we consulted across disability groups, sectors and government agencies. There was a sense that its benefits were self-evident, as one of the fundamental strategies for putting rights into practice.

> …if everyone's listening to me, then I'm much [more] likely to be living the life that I want to live and be free of those abuses. (Self-advocate)

Respondents considered that supported decision-making could benefit people with cognitive disabilities in multiple different ways; by safeguarding, empowering, improving wellbeing, emphasising the importance of social connections and furthering social change. From a broader perspective, supported decision-making done well was also seen as having the potential to save costs and improve the effectiveness of individual funding schemes such as the Commonwealth NDIS and Aged Care, or State and Territory schemes such as those of Transport Accident Commissions. However, as discussed below (at Section 8.2), some notes of caution were raised about supported decision-making and the dangers of seeing it as a panacea for service system problems.

1.5.1 Safeguarding

Most commonly, supported decision-making was identified as a strategy for ensuring the safety of people with disabilities and protecting them from abuse. Primarily this was because supported decision-making meant others, besides service providers, would be involved in the lives of people with disabilities. This broader involvement was seen not only as a deterrent to potential abusers but as a means of detecting abuse much sooner if it were occurring.[40] As one respondent said, 'harms occur behind closed doors'. In particular having more people involved in a person's life could reduce the vulnerable situation of people with more severe cognitive impairment who are unable to raise concerns about what is happening to them for themselves. In addition, the intention of supported decision-making was seen to provide a set of principles to guide all support to a person, potentially improving its overall quality. Respondents said, for example,

> If supported decision-making is in place, then there's theoretically an independent person or 2 or 3 people who assist a person in a process of decision-making, supported decision-making means that decisions are made in a way that respects rights, and a person's voice is heard – and these things point to prevention of abuse. (Advocate–generic)

> There's an intentionality with supported decision-making and principles guiding practice – so when that's happening, it's a significant safeguard. (Service provider)

> …to get really good supported decision-making, they will need and have more people in their life, more people around them, whether that's formally in a circle or a microboard, or whether it's just an informal network. But by having those people, the more eyes there are on a person who's got vulnerabilities, the safer they are, the less open to abuse and neglect. (Family–disability)

1.5.2 Empowering and furthering wellbeing

Respondents perceived supported decision-making as furthering the empowerment and self-determination of people with cognitive disabilities in a range of different ways. These included individuals experiencing: greater exercise of choice and control; support to navigate complex systems; assistance to understand information and explore a broad range of options; increased opportunities to make decisions, and a greater likelihood that decisions would reflect their preferences. By having more opportunities to make decisions and have one's choices respected, supported decision-making was also seen to further confidence, skills in self-advocacy and decision-making, and awareness of individual rights. Respondents said for example,

> if you have someone who is empowered to be involved and engaged in the decision-making about their own lives… the confidence and the competence that comes from that part I would think would be beneficial in terms of being able to… raise the alert should they be in a situation where they themselves I guess have awareness that something doesn't feel right… (Advocate–generic)

Both self-advocates and family members thought that supported decision-making helped to improve the emotional wellbeing of people with cognitive disabilities. This was because it meant people were more in control of their own lives, gained a greater sense of self and experienced less stress and frustration with their situation.

> There's a real difference with him – a smile, eye contact, when he gets what he wants. (Family member – disability)

> If you have the right supports, you can gain confidence – you do something with support (eg, catch a bus) and you end up having the confidence to do it on your own. (Self-advocate)

These findings are also consistent with research reported in the literature.[41] For example, in a study of the impact of training on parents' supported decision-making practice, several referred to the increased confidence of the person they supported when their own practice more closely aligned with the principles of supported decision-making.[42]

Although children and young people are not within scope of this Report, it is worth noting that the literature identifies the way children with a cognitive disability are subjected to heightened intensity and durations of informal substitute decision-making by families, especially around perceived risk.[43] While both law and family practice endorse parental decision-making for all children in their early years, this transitions into increasing recognition of rights to participation in decision-making, and ultimately taking responsibility for making their own decisions once they sufficiently understand the issues (the 'mature minor' principle). For children and young people with intellectual disability in particular, studies reveal that while,

> parents recognised the importance of their children experiencing a feeling of independence … they did not think that it was right to give them full independence in decision-making, especially regarding complex or important decisions where the need to protect them overcame the value of independence[44]

This legacy effect of extending informal substitute decision-making into late adolescence and early adulthood by paying no or inadequate regard to will and preferences seriously detracts from recognition of autonomy and dignity rights promoted through supported decision-making. Although children were not within the scope of this Report, such findings are relevant to the design of measures for full realisation of the equal right of all adults to 'make decisions that affect their lives and to have those decisions respected' (Principle 1 below).

1.5.3 Emphasising the significance of social connections

Some respondents thought that supported decision-making highlighted the significance of social connections to a good quality of life, and the actual dearth of connections beyond immediate service providers for many people with cognitive disabilities. By drawing attention to social connections, they thought supported decision-making acted as a catalyst for prioritising the development of networks. Emphasising social connections might also potentially lead to improved use of funding and in the longer-term cost savings. For example, supported decision-making might help to focus planners' and funders' attention on the purchase of support that aimed to build a person's social network over time, rather than, as often occurs at present, taking a short-term perspective such as paying for support to act as a companion for a person.

> Resources often used to getting someone out to a coffee shop – resource needs to be redirected into building networks and sustaining friendships. (Family–disability)

> we are massively overinvesting in housecleaning and delivered takeaways meals… Because we have not understood well enough the distinctive needs and we are under-investing in capacity building sort of work… there are economies of savings – there's probably 20% savings in some of the practical supports sort of costs… (Advocate–mental health)

While there is little evidence in the literature to support these propositions, overseas cost benefit assessments have suggested that overall savings might result if supported decision-making is embraced at a societal level.[45]

1.5.4 Furthering social change

The value of supported decision-making was also seen to be a powerful symbol influencing social attitudes by reminding others about the rights and personhood of people with cognitive disabilities. One respondent for example, drew attention to the impact of the low profile of supported decision-making in the aged care system.

> Because aged care staff don't know people still have a right to be involved in decisions, they are unintentionally supporting elder abuse in some cases. (Advocate–aged care)

In contrast a self-advocate commented that supported decision-making seemed to have changed attitudes towards him.

> Without supported decision-making there have been times that supporters have treated me like a child, telling us what to do, not as an independent person. We can feel like we're 'looked down upon a bit'. (Self-advocate)

Supported decision-making was seen to have driven the involvement of people with cognitive disabilities in decision-making beyond the personal, by modelling respect for their views to others around them in families, services, and social systems. In this way it served to illustrate and model the participation of people with cognitive disabilities not only in determining their own lives, but also in civil society. As one disability advocate said, supported decision-making was a way of 'translating values into things that are visible'.

1.6 Conclusion

This chapter has clarified fundamental understandings of the meaning and character of supported decision-making, identifying a principled approach as preferable to a binary understanding of the concept. It also identified the limits of supported decision-making and the exceptional circumstances where serious harm may result that may warrant substitute decision-making guided by a person's personal and social wellbeing as well as their will and preferences. The chapter has also identified some of its common benefits across diverse disability and service settings in which it may be practised. The next chapter examines the principles and key elements of a framework for supported decision-making, centred around diversity, dignity, equity and best practice.

Chapter 2. Principles and elements of the Diversity, Dignity, Equity and Best Practice Framework for supported decision-making

For the purpose of this Report, we understand a framework as akin to a skeleton, setting out the key principles and elements that must be considered when thinking about something (a structure, a program, an analysis) that is to be developed. It is a guide to thinking about a phenomenon rather than a set of procedures or instructions. The proposed Framework incorporates universal **principles** that inform all aspects of supported decision-making and **elements** that guide development and act as design imperatives for operationalising principles and the development of supported decision-making law, policy, and programs.

This chapter first briefly outlines the nine universal principles and eight elements recommended for the Framework. We then elaborate on the universal principles. The first four principles reflect those set down by the CRPD and ALRC ('ALRC principles'), with minor updating of the language from 'persons' to 'people'. The other five principles are based on the literature and this study's empirical work. The rationale and evidence underpinning each of the elements is then elaborated in separate chapters.

2.1 Overview of framework principles and elements

Universal Principles

Principle 1: The equal right to make decisions

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

Principle 2: Support

All people who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will, preferences and rights

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

Principle 4: Safeguards

Laws, legal and policy frameworks must contain appropriate and effective safeguards in relation to interventions for people who may require decision-making support, including to prevent abuse and undue influence.

Principle 5: Principled approach to supported decision-making

A principled approach to the concept and practice of supported decision-making should be adopted that keeps an individual's stated or perceived 'will and preferences' at the centre of decision-making. This approach recognises the realities of the practice of providing supported decision-making, particularly for those with severe cognitive disabilities.

Principle 6: Best interpretation of will and preferences

In the very limited circumstances where a supporter has not been able to elicit a person's will and preferences a decision should be made based on their best interpretation of what the person's will and preferences would be.

Principle 7: Dignity and risk

The dignity and importance of taking risk is acknowledged and supported. In very limited circumstances, where a person's stated or inferred will and preferences involve risk of serious, imminent physical or financial harm with lasting consequences to themselves (including incurring civil or criminal liability), and that person is unable to understand that risk even with support, a substitute decision can be made as a last resort with the person's personal and social wellbeing being, as well as will and preferences, guiding decision-making.

Principle 8: Distributional equity

All supported decision-making reform and initiatives should be premised on the ethical principle of a commitment to distributional equity of access to supported decision-making. Those experiencing disadvantage in accessing supported decision-making should be given priority in new programs.

Principle 9: Co-leadership of people with cognitive disabilities

People with cognitive disabilities and supporters of people with severe cognitive disabilities should lead consultation and design processes for supported decision-making reform and initiatives.

Elements

1. **Recognising diversity in supported decision-making** (Chapter 3)

   Recognising diversity will ensure that reform of law, policy and initiatives about supported decision-making accounts for the diversity of people with cognitive disability, as well as the diversity of contexts and supporters, and ensure that universal principles are translated into the types of programs and best practice that are appropriate to meeting diverse disability-related support needs, and also diverse social and cultural contexts.

2. **Interrelationship of supported decision-making with other systems** (Chapter 4)

   Recognising the interrelationship of supported decision-making with other systems acknowledges that it cannot stand alone and must be embedded in and connected to existing service systems with different institutional and legislative frameworks. A broad perspective should be adopted that considers, for example, how statutory supported decision-making can fit into other parts of the policy and legislative landscape.

3. **Use of best practice and ethical supported decision-making** (Chapter 5)

   Use of evidence-informed best practice frameworks in supported decision-making should be central to all supported decision-making programs and initiatives.

4. **Capacity building at individual, system and institutional levels** (Chapter 6)

   Capacity building at the individual, system and institutional level must be a key strategy for implementing all aspects of a Framework for supported decision-making.

5. **Safeguarding, quality assurance and oversight** (Chapter 7)

   Approaches to safeguarding, quality assurance and oversight should be adopted using strategies that best meet the needs of the different settings in which supported decision-making occurs and are proportionate to risk.

6. **Enabling forward planning** (Chapter 8)

   All legal instruments for forward planning should reflect a principled approach to supported decision-making to minimise the potential for future best interests substitute decision-making remaining the default option in these instruments. The range of forward planning legal instruments should be expanded to allow for the appointment of supporters and enduring supporters.

7. **Adequate funding** (Chapter 8)

   Provision of adequate funding is needed to enable supported decision-making to be implemented within and across sectors and jurisdictions in Australia. This bespoke national funding should be separate from and additional to, reliance on funding from service packages in Commonwealth, State or Territory schemes such as the NDIS, Aged Care, and other individualised funding packages for support for people with cognitive disabilities.

8. **Strategies to build social connections** (Chapter 8)

   Strategies to build social connections of people with cognitive disabilities who are socially isolated should be a priority investment in supported decision-making programs and initiatives.

2.2 Universal principles of the Framework

As elaborated in Chapter 3, supported decision-making needs to be implemented for people with diverse cognitive disabilities and different decision support needs across diverse social, cultural, legal and institutional contexts, as well as for diverse types of decisions. Operationalising a framework for supported decision-making will be different in different contexts. However, the overarching principles of the framework need to be universal, encompassing all people with cognitive disabilities, all service sectors and jurisdictions across Australia, and all types of decisions. Focus group respondents supported the need for a universal framework. They said for example,

> Principles need to be universal – not applicable to any one disability.
> (Advocate–mental health)

The grounding principles for supported decision-making have been largely ideological, derived from the international human rights and other high-level values reflected in the CRPD. These include privileging human autonomy and agency, the equality principle, and rejecting capacity-based evaluation and best interests substitute decision-making. Our research suggests however that a Framework for supported decision-making that is universal and that can be operationalised in practice, needs additional principles to those of the CRPD, as elaborated in this chapter.

2.2.1 Adapting the Australian Law Reform Commission operationalisation of CRPD principles

The foundations of our Framework are the ALRC principles as drawn from human rights principles and article 12 of the CRPD. They have been widely endorsed in Australia and recognised internationally.[46] These remain relevant and provide an excellent starting point for development of the universal principles informing our framework for supported decision-making. These 4 principles are:

- **The equal right to make decisions** – All adults have an equal right to make decisions that affect their lives and to have those decisions respected.[47]
- **Support** – All persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.[48]
- **Will, preferences and rights** – The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.[49]
- **Safeguards** – Laws, legal and policy frameworks must contain appropriate and effective safeguards in relation to interventions for people who may require decision-making support, including to prevent abuse and undue influence.[50]

The ALRC principles were known to many focus group respondents who largely thought these were very relevant as foundational principles of supported decision-making. Respondents commented that the ALRC principles were,

> very clear and aligned with supported decision-making. (Service provider)
>
> very straightforward and that's really helpful. You don't want a lot of complicated stuff… they allow some human movement and flexibility as well …in shades of grey, that you're not told that everybody can be supported, and everyone can make their own decisions. And that's not always the case. (Advocate–disability)

Several respondents did suggest the ALRC principles might benefit from updating to reflect changes since they were drafted. One concern was about the outdated language,

> …whenever I show them to staff, they're like, "Ew." They don't like the language and stuff…. since 2014, times moved on a little bit and they would benefit from a review, "Is this really the language they're after? Is it saying what we really want them to say?" (Advocate–disability)

For example, the formal language of 'persons who require support in decision-making should be replaced with everyday language of 'people'. We agree with this comment and in our recommended principles have amended 'persons' to 'people'.

The ALRC also proposed three sets of guidelines on: support; will, preference and rights; and safeguards. Where relevant we have incorporated the substance of these into elements of the Framework (see Chapters 3 and 5). More holistic legal reform has been proposed by the NSWLRC's report, but law comprises only a small part of what is needed. The ALRC Report recast some powers within the narrower Commonwealth sphere, such as those of 'nominees' and articulated model principles to guide State and Territory reforms. However, law reform bodies such as these have been silent on service systems, resourcing, and the informal civil society arrangements as this is neither their brief nor do they have expertise to address these questions. As we have emphasised, a supported decision-making Framework is about much more than law and law reform and must also be policy and practice orientated.

In Chapter 1, we discussed the lack of shared understanding about supported decision-making among both key stakeholders and the public. We propose as a fifth principle that overall, a principled approach to supported decision-making be adopted. This will assist in developing shared understandings of supported decision-making and avoid the exclusion of people with severe cognitive impairments from its benefits. As already set out, the principled approach to supported decision-making does not draw a clear distinction between supported and substitute decision-making and in practice, the relevant marker of supported decision-making is that an individual's stated or perceived 'will and preferences' remain at the centre of the decision.

Principled approach to supported decision-making – A principled approach to the concept and practice of supported decision-making should be adopted that keeps an individual's stated or perceived 'will and preferences' at the centre of decision-making. This approach recognises the realities of the practice of providing decision support, particularly for those with severe cognitive disabilities.[51]

To make explicit that supported decision-making does apply to people who may not be able to directly express their preferences or actively make a decision we propose as a sixth principle – 'best interpretation of will and preferences.'

Best interpretation of will and preferences – In the very limited circumstances where a supporter has not been able to elicit a person's will and preferences, a decision should be based on their best interpretation of what the person's will and preferences would be.[52]

The limitations of supported decision-making caused by risk aversion were discussed in Chapter 1 and we propose an additional principle of 'dignity and risk' that reflects our recommendation about the limitations of supported decision-making, recognising the significance of risk for decision supporters.

Dignity and risk – The dignity and importance of taking risks is acknowledged and supported. In very limited circumstances where a person's stated or inferred will and preferences involve risk of serious, imminent physical or financial harm with lasting consequences to themselves (including incurring civil or criminal liability), and that person is unable to understand that risk even with support, a substitute decision can be made as a last resort with the person's personal and social wellbeing as well as will and preferences guiding decision-making.[53]

2.2.2 Distributional equity

Distributional equity of access to support is the eighth universal principle of our Framework. Engagement with principles of distributional equity is lacking in the ALRC principles, and only inferentially found in the CRPDs 'right to support'.[54] Although the ALRC recognises that people who require it must be provided with support for decision-making, there is no acknowledgement of deep social and geographic inequities in access to such support. This, in our opinion, is no small oversight.

Support cannot be delivered without a supporter or supporters of some kind. Yet many people with cognitive disabilities, who need or would like to be supported are without unpaid social relationships of any kind or are of an age or in a location such that unpaid supporters are not available to meaningfully provide (or continue providing) that support.[55] Many people rely therefore on paid supporters for decision-making who are service providers. Some of these paid supporters (though not all) especially in the case of people with intellectual disabilities, may have known them for many years. However, service providers face continual conflicts of interest as decision supporters and also have limited capacity, due to funding limitations and time constraints, to take on supported decision-making roles over and above their day-to-day responsibilities.

Recruitment of volunteers willing to fill these voids and act as supporters is both difficult and costly. Pilots suggest that identifying and engaging with people without social connections is challenging, as is facilitation of volunteer supporters.[56] It is perhaps telling that an Israeli study recommended that volunteer supporters be remunerated.[57] Suggested remedies such as registers of potential supporters or expecting people to nominate a supporter ahead of when they need one, will not address the cold hard reality that for socially disconnected groups supported decision-making will have a significant cost.

All focus group respondents recognised the deep inequities of access to supported decision-making among people with cognitive disabilities. The most disadvantaged were seen to be people without strong and resourceful family or informal networks without any relationships outside service systems, and those with severe cognitive disabilities for whom expression of preferences and participation was the most difficult. Redressing the inequity for these groups in accessing support was seen as a priority for any new resources for supported decision-making programs. For example, resources could be directed at establishing formal supported decision-making programs that fund the appointment of long term paid independent decision supporters and proactive building and maintenance of a circle of supporters. Thus, supported decision-making initiatives should compensate for inequities in the availability of informal unpaid supporters and access to supported decision-making rather than benefit only those with existing strong networks. As focus group respondents said,

> …because if you have a skilled family, you are greatly advantaged. (Advocate–mental health)

> if you don't have close relatives or don't really have much support, the government needs to provide it. (Self-advocate)

Both the literature review and our focus groups highlighted the social isolation and lack of unpaid decision supporters in the lives of many people, including NDIS participants, one of the highest priority groups. For this reason, we propose as the eighth principle, commitment to distributional equity of access to supported decision-making.

Distributional equity – All supported decision-making reform and initiatives should be premised on the ethical principle of a commitment to distributional equity of access to supported decision-making. Those disadvantaged in access to supported decision-making should be given priority in new programs.[58]

This principle will help to ensure that when new programs are designed or initiatives begun, they are targeted at those without unpaid supporters and who have the greatest need for supported decision-making. Adding a principle of distributional equity and taking a targeted approach to programs and implementation will not be a panacea. But its inclusion strengthens the prospects for design and delivery of programs that are adequately resourced and meet the needs of those without adequate decision support.

2.2.3 Co-leadership by people with cognitive disabilities

A core principle of the CRPD is 'nothing about us without us'. People with disability are experts by lived experience, and a supported decision-making reform without co-leadership contradicts the very logic of self-determination that underpins the Convention.

Several focus group respondents raised the importance of including people with cognitive disabilities in leadership, consultation and design processes for supported decision-making programs. Their absence from law reform processes and debate about supported decision-making was seen as one of the reasons for the slow progress of reform. One disability advocate who proposed that any framework should include people with cognitive disabilities in leadership of supported decision-making and program design, explained,

> Yeah. I think that people with disability really do need to genuinely be part of the process and I think there should be some requirements even about employing people because again, it’s a cultural change for the organisation itself. And I think part of the reason why we don’t have legislative change is because none of the people who are involved in decision-making are people with disability or kind of any skin in the game. We might have someone who happens to have a family member, but it’s not integral to the decision-making process. So, I think that just entire absence of experience is problematic, so I think the presence of people in genuine co-design or genuine consultation should be built in somehow. (Advocate –disability)

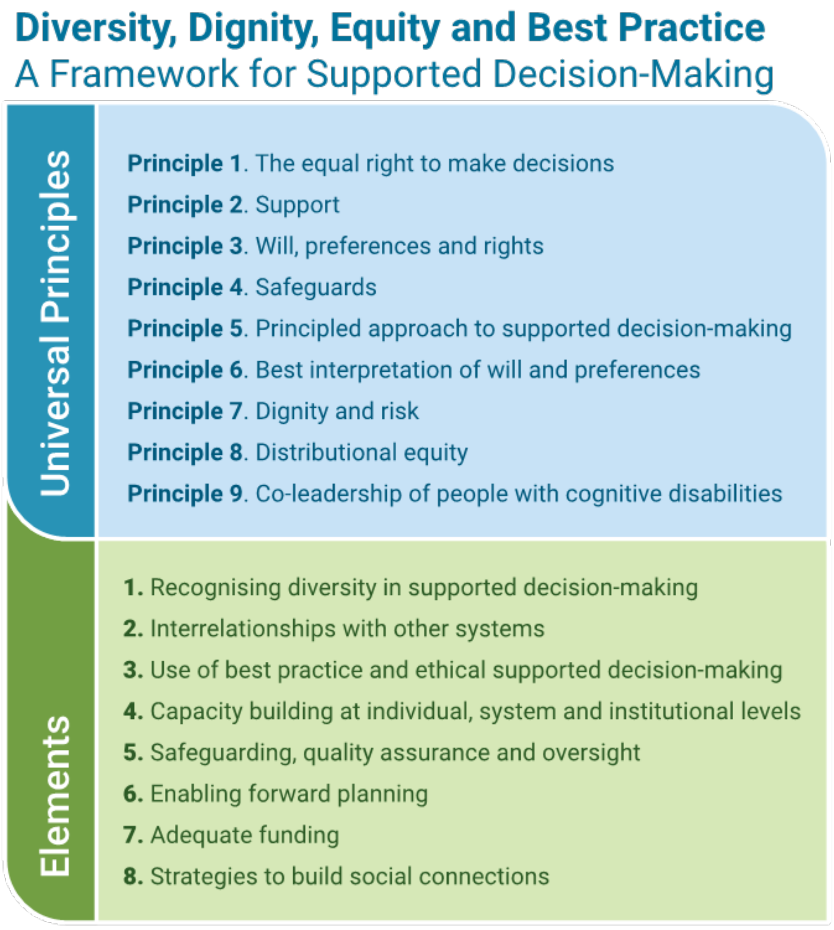
An Australian qualitative study with 12 adults with mild intellectual disabilities found that participants were able to identify potential risks and safety issues and discuss measures that could be used to keep them or someone else safe. Drawing from their own lived experience, participants were found to strategically use support workers or informal carers in their decision-making process. The authors conclude that: ‘it would appear that trusted relationships should form an integral part of a co-created and individualised approach to safeguarding.’[59]

The literature and our field work identified limited inclusion of issues facing people with severe cognitive impairments in debate or research about supported decision-making. For this reason, and to address the difficulties of representing the perspective of others who may have a very different experience from one’s own, we propose that co-design around supported decision-making should also include families and supporters of people with severe cognitive disabilities. Their involvement will help to ensure issues particularly relevant to people with severe cognitive disabilities are considered in design, as well as those relevant to people who are able to represent their lived experience directly. Also, given the centrality of supporters’ practice to good supported decision-making, we suggest that co-design draw on the lived experience of informal and formal supporters so that it can take account of the dilemmas they face and types of skills and strategies they consider necessary for good support. We therefore propose as a ninth principle:

Co-leadership of people with cognitive disabilities – People with cognitive disabilities and supporters of people with severe cognitive disabilities should lead consultation and design processes for supported decision-making reform and initiatives.[60]

2.3 Summary

We propose a framework for supported decision-making in Australia that encompasses all jurisdictions, service systems, people with cognitive disabilities, types of decisions and context. We propose calling it: a ‘Diversity, Dignity, Equity and Best Practice Framework for Supported Decision-Making’ (‘the Framework’). As depicted in Figure 1, it should include nine universal principles (as enumerated above) and eight elements that will guide development and act as design imperatives for operationalising the principles of supported decision-making and development of supported decision-making law, policy, and programs.



Diversity, Dignity, Equity and Best Practice
A Framework for Supported Decision-Making

Universal Principles

Principle 1. The equal right to make decisions
Principle 2. Support
Principle 3. Will, preferences and rights
Principle 4. Safeguards
Principle 5. Principled approach to supported decision-making
Principle 6. Best interpretation of will and preferences
Principle 7. Dignity and risk
Principle 8. Distributional equity
Principle 9. Co-leadership of people with cognitive disabilities

Elements

1. Recognising diversity in supported decision-making
2. Interrelationships with other systems
3. Use of best practice and ethical supported decision-making
4. Capacity building at individual, system and institutional levels
5. Safeguarding, quality assurance and oversight
6. Enabling forward planning
7. Adequate funding
8. Strategies to build social connections

Figure 1. Diversity, dignity, equity and best practice: A Framework for supported decision-making

Recommendation 1 Nine universal principles should inform the Framework for supported decision-making:

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

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

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

Principle 4: Safeguards. Laws, legal and policy frameworks must contain appropriate and effective safeguards in relation to interventions for people who may require decision-making support, including to prevent abuse and undue influence.

Principle 5: Principled approach to supported decision-making. A principled approach to the concept and practice of supported decision-making should be adopted that keeps an individual's stated or perceived 'will and preferences' at the centre of decision-making. This approach recognises the realities of the practice of providing supported decision-making, particularly for those with severe cognitive disabilities.

Principle 6: Best interpretation of will and preferences. In the very limited circumstances where a supporter has not been able to elicit a person's will and preferences a decision should be based on their best interpretation of what the person's will and preferences would be.

Principle 7: Dignity and risk. The dignity and importance of taking risks is acknowledged and supported. In very limited circumstances, where a person's stated or inferred will and preferences involve risk of serious, imminent physical or financial harm with lasting consequences to themselves (including incurring civil or criminal liability), and that person is unable to understand that risk even with support, personal and social wellbeing substitute decision-making is applied as a last resort with the person's personal and social wellbeing at the centre.

Principle 8: Distributional equity. All supported decision-making reform and initiatives should be premised on the ethical principle of a commitment to distributional equity of access to supported decision-making. Those experiencing disadvantage in access to support for decision-making should be given priority in new programs.

Principle 9: Co-leadership of people with cognitive disabilities. People with cognitive disabilities and supporters of people with severe cognitive disabilities should lead consultation and design processes for supported decision-making reform and initiatives.

Recommendation 2 Eight elements be included in the Framework.

- Element 1: Recognising diversity in supported decision-making
- Element 2: Interrelationship of supported decision-making with other systems
- Element 3: Use of best practice and ethical supported decision-making
- Element 4: Capacity building at individual, system and institutional levels
- Element 5: Safeguarding, quality assurance and oversight
- Element 6: Enabling forward planning
- Element 7: Adequate funding
- Element 8: Strategies to build social connections

Chapter 3. Recognising diversity in supported decision-making

This chapter turns to the first element of a supported decision-making framework: recognising diversity. The ALRC was largely silent on accommodation of diversity and the flexible translation of supported decision-making principles to particular sub-groups, life course stages or service systems. In the previous chapters we have highlighted the differences in the severity of cognitive disability, and how these must be accommodated by the principles of supported decision-making. In this chapter we examine other aspects of the diversity of people with cognitive disability, including their disability groups, socioeconomic situations and cultures. Diversity among decision supporters is discussed in Chapter 5. We stress here how important it is for a framework of supported decision-making to take account of and accommodate for diversity.

3.1 Diversity of people and supported decision-making needs

This section discusses developments in supported decision-making for different disability groups. While we have segmented the literature according to disability groups, we also recognise that many people will have more than one impairment or health condition – for example, a person with a mental health condition may also experience dementia as they age, people with ABI have a high incidence of mental health conditions, some people with intellectual disabilities also have mental health conditions and a high proportion of people with Down Syndrome experience the early onset of dementia as they age.[61] Individuals will also experience intersectional vulnerability, when a particular disability co-occurs with other experiences or contexts (eg, socio-economic disadvantage, speaking English as a second language etc.) which leads to intersecting forms of disadvantage. However, we try to capture some of the features common to each group (a more detailed consideration is found in Appendix A).

3.1.1 People with intellectual disabilities

Adults with intellectual disabilities tend to have relatively stable cognitive abilities. They do not experience episodic loss of decision-making ability (more common in mental health conditions) or gradual decline (as experienced by people with dementia) unless they also experience dementia in mid or later life. Adults with intellectual disabilities make up 28.5% of NDIS participants over 25 years of age. They are the largest group of adults in the scheme and are more likely to be participants in the NDIS than people with dementia or mental health conditions.

Supported decision-making initiatives for people with intellectual disabilities began in Canada in the 1990s before the development of the CRPD.[62] Building on these foundations, since the adoption of the CRPD in 2006, debate around supported decision-making has focused on people with intellectual disabilities more than on any other disability group. There has been a particularly strong emphasis on the impact of removing rights that goes hand in hand with best interests substitute decision-making. This stems from the legacy of Kantian philosophy and the historic denial of rights to people with intellectual disability on the grounds that they lacked rational thought and autonomy.[63]

People with intellectual disability have quite different trajectories of decision support needs from other groups, their needs being lifelong. Past low expectations of children and adults with intellectual disabilities to participate in decision-making, protective environments and limited availability of empowering support, mean that many of these adults will have accumulated little experience in decision-making.

> People with Downs Syndrome can get dementia – historically they wouldn't have had ability to express preferences but this is changing – but people with dementia without other disabilities have a history of making their own decisions. (Advocate– aged care)

Comments from focus group respondents suggested that attitudes and opportunities were changing, with an increased focus on building decision-making experiences and skills of people with intellectual disabilities 'from the get-go'. One respondent contrasted contemporary attitudes about this group with those about older people with dementia,

> …for people with intellectual disability there is an approach of building up capacity but in dementia there is declining capacity [and] not trying to develop it for good life. (Advocate–aged care)

As this quote suggests, people with intellectual disabilities continue to develop decision-making skills throughout their lives. They are more likely than other groups to live with their parents well into midlife and receive long-term support from family members even if they do move to supported accommodation. Importantly, however, they do not all have strong or resourceful family support.[64]

There has been more research and evidence established around supported decision-making with people with intellectual disabilities than other disability groups.[65] Most pilots and programs nationally and internationally have included majority cohorts of participants with intellectual disabilities.[66] Within Australia, participants with intellectual disabilities have been the focus of the La Trobe Support for Decision-making Practice Framework ('La Trobe Framework') together with people with ABI. This evidence-based framework forms the basis for education and training for supporters to provide effective decision-making support to people with intellectual disabilities and ABI. An evaluation using qualitative and quantitative methods showed parents of adults with intellectual disabilities trained in the La Trobe Framework were more self-reflective about their decision support and took a more deliberative approach to supporting decision-making that indicated greater use of supported decision-making principles and strategies.[67]

3.1.2 People with acquired brain injuries

ABI can be acquired at any point in a person's life and can result in a person changing physically, cognitively, and emotionally.[68] Such changes frequently include increased stress and poor mental health.[69] In Australia, at least 1 in 45 people are living with ABI and have associated activity limitations or participation restrictions.[70] 'Further almost three-quarters of these people are aged less than 65 years and experience the ongoing challenges of adjustment to chronic disability.'[71]

A unique feature of cognitive disability associated with ABI is its sudden impact, and over time, with effective support, cognitive improvement and the reconstruction of identity.[72] People with an ABI, similar to people with dementia, will have made decisions mostly independently before their injury. As noted by Wiesel et al.,

> After an injury, many people with ABI continue to self-identify with personal attributes or characteristics from before the injury, alongside some newly recognised attributes shaped by experiences after the injury. Yet, the injury and its consequences often mark a significant temporal boundary – or discontinuity – in terms of personal goals. After their injury, striving to live well with their impairment, many people reassess their personal goals which continue to change over time.[73]

A consequence of this is that supporters who knew the person before their injury have to grapple with the extent to which the person's psychological and emotional self has changed since the injury.[74]

The La Trobe Framework was implemented by a small number of TAC coordinators whose clients had ABI. They were trained in the La Trobe Framework with materials adapted to people with ABI and the TAC's context of decision-making. The qualitative and quantitative results from that small study demonstrate that training in the La Trobe Framework had a significant impact on supporters' confidence and demonstrated a significant shift in supporters' reported strategies towards effective supported decision-making practices in dealing with their clients with ABI.[75]

3.1.3 People with dementia

People with dementia are more likely to be older individuals who experience a gradual decline in decision-making abilities, however such decline is not necessarily linear in its progression.[76] They are much more likely to be using services from aged care rather than disability service systems. The changing nature of their decision-making capacities distinguishes them from groups whose capacity is more stable, such as people with intellectual disabilities. Also distinguishing them is the likelihood that they will have lived much of their lives making independent decisions and may have acquired professional or community responsibilities and/or amassed significant assets and connections during their lifetime.[77] This is also likely to be the case for people with early onset dementia, other than those with Down Syndrome (among whom this condition is particularly prevalent).

Some people with dementia may also have chosen to plan ahead, utilising forward planning mechanisms to ensure that their wishes are known, and that trusted friends or family have legal authority with respect to certain decisions.[78] Research shows that a transition from supported decision-making to substitute decision-making is normally anticipated. Sometimes this relinquishment of decision-making is at the wishes of the person with dementia but may also be initiated by family members who consider cognitive decline has reached a point where supported decision-making is impossible or are worried about an individual's safety.[79]

Unlike people with the cognitive impairments associated with other disabilities, people with dementia and their advocates were not included in negotiations and drafting of the CRPD.[80]

However, focus group respondents noted that today, the view is gaining ground that people with dementia have a right to have their preferences recognised and be consulted about their care and other decisions.

A challenge identified in providing supported decision-making for people with dementia, is how to manage a person's past and present will and preferences, given that these may not align.[81] The question of how much weight to give precedent autonomy as compared with expressed current wishes in the context of providing or implementing supported decision-making is unclear.[82] One focus group respondent captured this challenge when she said that,

> …you'd think about trying to make the decision that the person would've made. And that's really great. In a lot of occasions, you're trying to do something that's consistent with their life choices...But the challenge then is when their dementia means their choices change, so the people they want to hang out with are different or – I don't know – the music they like is music they've never listened to, and the things they want to do, they might've been horrified as a younger person to see it. But that doesn't mean that that choice and preference isn't very real for that moment…. And that's the challenge, isn't it, of advance directives and all of those things, because you shift to be a different person. (Advocate – general)

Barriers to successful supported decision-making in residential aged care facilities are identified in the next chapter (at Section 4.2.2); and for people with dementia in a family setting, barriers include time constraints, burnout among carers, conflicts of interest with other family members, and financial constraints on options available.[83]

There have been few pilots of supported decision-making involving people with dementia. In Australia, the Cognitive Decline Partnership Centre has developed generic training for aged care staff on supported decision-making focusing on people with dementia.[84] Other pilots or programs internationally focus on people with dementia and participation in research (the ENSURE project) and health decision-making (PRODECIDE).[85]

3.1.4 People with mental health conditions and psychosocial disabilities

The wide variety of mental health conditions and the many ways in which these are experienced, mean that decision-making processes and the needs of people with mental health conditions vary considerably. Many experience no issues with their decision-making abilities, or else successfully manage decision-making informally – they experience mental illness but not psychosocial disabilities. For others, episodic or ongoing mental health conditions have a severe impact on their lives and are associated with a high need for supported decision-making. In general, it is possible to identify features of mental health conditions which distinguish them from intellectual disabilities, ABIs and dementia. Mental health conditions are more likely to have a changing or fluctuating impact on a person's ability to make decisions. Some mental health conditions are characterised by episodic periods where greater intervention and treatment occurs. The episodic nature of mental illness has generated debates about tensions between long term or enduring will and immediate preferences.[86]

Conceptual understandings and supported decision-making initiatives tend to be distinct for this group from those that arise in relation to other disabilities. Much of the focus for this group has been on decision-making during episodic crises, and differences from other groups may be partly attributed to the separate and distinct legal frameworks that many countries have for mental health treatment;[87] and the fact that coercion and involuntary treatment has been a characteristic of treatment provision. However, respondents recognised that there is a growing rights perspective for people with mental health conditions and involuntary treatment legislative provisions, often underpinned by questions of capacity (similar to the general health sector), have been criticised by the CRPD Committee.[88] As one respondent said,

> In mental health – supported decision-making is less developed. It gets to a certain point where someone is so unwell they are disenfranchised from their support network because of their complex behaviour. This means that the supported decision-making framework falls apart. (Service provider)

Research has found that some clinicians have long-standing therapeutic relationships with their patients and know them well, so they are particularly well placed to support their decision-making. Similarly, focus group respondents suggested that supported decision-making should be incorporated into everyday practice of professionals practising in mental health, such as NDIS recovery coaches.

Conversely, where clinicians do not cultivate these types of supportive relationships, people with mental health conditions find it difficult to participate in decision-making, including on treatment.[89] For most people in this group, the role of family and peer support is highly valued.[90] However, supporters have found their role difficult, being excluded from access to information or participation in decision-making with the person they are trying to support or finding themselves conflicted in their role.[91] The importance of supporters having good interpersonal skills and strong relationships with the supported person are seen as key to the success of supported decision-making in the mental health context,[92] which requires ongoing rather than episodic engagement of supporters.

The literature identifies several types of community programs[93] that seem to provide more than just decision-making support but have nevertheless been considered by commentators to fall within the ambit of supportive decision-making mechanisms and tools. These include the clubhouse model,[94] WHO QualityRights, circles of support,[95] peer support/advocacy[96] and open dialogue.[97] As well as these, participants with mental health conditions were included in a minority of supported decision-making pilots in Australia and internationally.[98]

The next section of this chapter considers what is known about supported decision-making in relation to particularly disadvantaged sub-groups of the Australian population.

3.2 Minority and disadvantaged population subgroups

In addition to different types of impairment, people with cognitive disability are also diverse in their gender, cultural background, socioeconomic status, and other aspects of identity. The intersection of disability with other aspects of identity generates different experiences and needs in support for decision-making that is culturally appropriate. In this section we focus specifically on people with cognitive disabilities who also identify as First Nations peoples, culturally and linguistically diverse, or LGBTIQ, as groups experiencing additional forms of marginalisation and disadvantage.

3.2.1 First Nations peoples

The Disability Royal Commission has conducted research with First Nations Peoples' who have given voice to their experiences of violence, abuse, neglect and exploitation, such experiences being felt both firsthand and inter-generationally.[99] There is however little published research specifically addressing supported decision-making in the context of First Nations peoples. Clapton et al identify issues affecting capacity to deliver supported decision-making for First Nations peoples, including: intergenerational trauma; mistrust and suspicion of existing guardianship and administration systems; a lack of cultural awareness and understanding of Indigenous people's history, kinship responsibilities, cultural values and beliefs and ways of working in state-led support systems; a cultural incongruence between Indigenous and Western worldviews in relation to individualism, collectivism and decision-making; barriers to accessing support services, such as language barriers, stigma and shame; and cultural bias in systems designed to assess cognitive (and decision-making) capacity.[100] Similar themes are identified in literature on end-of-life decisions by Indigenous peoples in New Zealand, Canada and the United States.[101]

The lack of published research is significant as there are higher rates of disability in First Nations communities as compared with other Australian communities and:

> …the nature of disability as experienced by this group is predominantly (but not only) related to mild to borderline intellectual disability, very often in combination with a range of mental health issues. Moreover, many people within this population group have a high incidence of acquired brain injury. The combination of these issues impacts significantly upon the person's daily functioning and can result in compounding social disadvantage and complex service-related needs.[102]

While not referring specifically to supported decision-making, Baldry et al advocate for culturally appropriate 'person centred support' for First Nations peoples with mental and cognitive disabilities.[103] The need for culturally appropriate information and training for government agencies interacting with First Nations people with disability is recognised by statutory bodies, such as the Office of the Public Advocate (Vic), which has published guidance for its staff on interacting with First Nations clients.[104]

The barriers faced by First Nations peoples was briefly considered in the Commonwealth Department of Social Services commissioned report on supported decision-making.[105] That research made the point that due to the mistrust in the sector, ‘Capacity building must also be sensitive to historical and current factors affecting the relationship between communities and government/services’.[106]

The NSWLRC noted that supported decision-making aligned closely with the:

> collaborative and communal style of decision-making in First Nations communities, particularly where there are multiple supporters. However, somewhat different from supported decision-making an individual’s decision is often thought of as a decision by and for their whole family or community group.[107]

Many focus group respondents raised questions about the applicability of a Eurocentric individualised approach to supported decision-making to First Nations peoples with disabilities, referring to the community based and collective approach to decision-making by indigenous cultures. One respondent explained this approach in some detail,

> we see it very much as our community is a collective community. Supported decision-making for a person that has a disability or doesn’t have a disability is often the same. It’s always a group consensus about what can and can’t be done particularly in more rural, regional and remote communities…. And because we have a very well-built understanding of our governance structure and our authority structures, we know who needs to be part of the decision-making process. We have been doing circles of support long before it became known as circles of support. … And literally we do sit and decide who is going to make the decision and who needs to be involved in that decision-making process. And it doesn’t mean that we’re taking away the autonomy of the individual. The individual is still centred but the decision is collectively made about what’s best for that person. And literally it is our way of doing the circle of support whether you have a disability or not… We hear what they want to – we hear what they say. We know what they mean through either their behaviour, their words and then we’ll sit down and have a discussion about what’s the best way to support that individual to do what they need to be able to do.
>
> For us, we would say in the framework it’s codesigning with the person if we’re going to use white person language. But that’s the outcome of supported decision-making. The principle is to get the individual to have a sense of agency about their own life and the principle is based on belonging. It has to – every time we’ve seen change in an Aboriginal person with a disability, it’s because they belong. That is the principle. That is unwavering. That gives the person a sense of individual agency because they know there’s a level of trust to be supported as people that make decisions. That’s the most profound thing if that makes sense. The second is understanding that cultural safety. Out of that sense of trust comes cultural safety. I feel safe with you. I feel safe with this organisation because the organisation has changed its systems and its method of working by having cultural safety. (Service provider)

There was, however, some evidence of confusion among some respondents between a collective approach to decision-making by First Nations peoples (such as that described above) and an individualised approach to supported decision-making which relies on a group of supporters, but which retains a focus on the individual decision-maker (such as microboards) and might not be culturally appropriate.

Despite these challenges, the NSWLRC in its report recommending the implementation of supported decision-making legal reforms noted that:

> A formal supported decision-making regime may provide a more culturally appropriate form of decision-making assistance for Aboriginal people and Torres Strait Islanders than substitute decision-making currently does.[108]

They recommended that historical, systemic disadvantage experienced by First Nations people needed to be recognised and specifically provided for in guiding principles for people exercising decision-making (including proposed supported decision-making) functions in the guardianship system.[109]

3.2.2 People from culturally and linguistically diverse backgrounds

There is also an absence of literature about the practice of supported decision-making amongst people from culturally and linguistically diverse backgrounds. While it is likely that people from different backgrounds and cultures have participated in research, to date no studies have reported findings focussed on the impact of participants' cultural background on conclusions drawn about supported decision-making.

In one study of aged care residents, a comment was made that for refugees who had arrived in Australia with few possessions, access to cash was a strong preference in their financial decision-making.[110] Zannettino et al describe the literature as acknowledging that older people from culturally and linguistically diverse backgrounds are 'particularly susceptible to financial abuse by their family members'.[111] They further write that the nature of this vulnerability is underexplored, but is exacerbated by cultural expectations around family privacy and also by the adults' dependency on others for 'translation of financial transactions, and services.'[112]

The Canadian Centre for Elder Law, in researching barriers to supported decision-making in investment decisions, noted that cultural background could lead financial advisors to misinterpret behaviours and communications.[113] Sinclair et al's research on the views of people with dementia and their family members on supported decision-making, noted the participants' countries of birth and mention that one woman 'had pressure culturally' to nominate her son as an enduring power of attorney rather than her daughter, but no further analysis of cultural issues is explored.[114] They recognise the need to 'undertake broader consultation with diverse community groups…' and 'culturally-specific service provider organisations' on supported decision-making for people with dementia.[115]

A 2021 scoping review of literature on cultural differences in decision-making practices by, with and for youth with intellectual disabilities transitioning to adulthood, found indications of differences in decision-making between those cultures that prioritised individuality, as opposed to those that prioritised family and community. The review concluded that the impact of cultural diversity on decision-making and people with intellectual disabilities is under-investigated, and that further research was needed so as to develop effective supported decision-making.[116]

3.2.3 People who identify as LGBTIQ

A gap in the literature exists about supported decision-making and those with a cognitive disability who identify as LGBTIQ. Only one unpublished paper on guardianship and LGBTIQ people was found that also mentioned supported decision-making as a potentially preferable alternative to ensure that consideration of the adult's identity was central to decision-making.[117] This extremely low yield is consistent with findings that there has been a lack of research generally on issues affecting people with intellectual disabilities from LGBTIQ communities.[118] The little there is suggests disability service systems demonstrate little capacity to adjust support to the needs of this group. Despite the breadth of stakeholders involved in the focus groups, they were silent on this group.

3.3 Why recognition of diversity should be a key principle of a supported decision-making framework

As the forgoing has illustrated, supported decision-making is understood and translated into practice in multiple and diverse ways through different programs, pilots and practices, for different disability groups, for different types of decisions and in different national, sectoral, cultural and everyday contexts. Supported decision-making may be a natural and almost undetectable aspect of social life, an explicit but unregulated practice, a practice given legal recognition, or a formal legal mechanism for channelling the way support is provided. It is not a boiler plate product that comes in one standard form or size. As a self-advocate respondent said, 'trying to come up with one size fits all won't work'.

Focus group respondents recognised the diversity encompassed by supported decision-making, and the importance that an overarching framework take account of that diversity. They saw this as helping to ensure that high level principles are translated into the types of programs and best practice applicable to whatever context or with whomever supported decision-making is implemented. Respondents said for example:

> Need generic frameworks legally – that allow for various forms of support to suit circumstances and needs. (Family-disability)

Respondents were also keen to ensure supported decision–making could be implemented in ways that gave people choices about how, by whom and under what conditions they would be supported. For example, one responded recalled,

> …someone saying they didn’t want to have a friend helping them. They wanted to go and see a professional for support because they wanted to keep that clear line about who did what and they probably still go to their friend about some kinds of decisions, but for supported decision-making as a proper thing, they wanted to pay for it, they wanted to go somewhere and talk to someone. And that was just that person and there would’ve been other people that had a completely different idea. (Advocate–disability)

This not only spoke to the importance of choice but also to the need for continuing evolution of different types of supported decision-making programs and practice which draw on a shared set of universal principles.

> …whatever you’re doing we should agree to a set of principles ... because then that gives people the freedom to work out what type of relationship they want and then you can have some innovation there as well, like that guy who said he wanted a professional, well, maybe that’s in his plan that, he gets to go and employ a decision–making supporter to help him work through what he wants to do… Or maybe there are peer groups where people set up groups to help each other learn about different issues and then make decisions. It depends what you want them [decision supporter] to do. (Advocate–disability)

Focus group respondents were clear that design of specific supported decision-making programs should be shaped by the target group, sector, or specific types of decisions or risks.

> Would like to see formal systems available for people dealing with different government agencies, services and legal systems. (Advocate–disability)

> Policy doesn’t need to be generic because you need the expertise of those who are more familiar with particular groups. (Family–disability)

They commented on their experience of pilot or established programs rather than suggesting blueprints for new programs (see the Appendices A and C for details about these). Thus, the features of the programs mentioned were diverse, including: drawing up supported decision-making agreements; resourcing and monitoring informal supporters; finding and matching new supporters to people without informal supporters; appointing and supporting a decision supporter for specific sets of decisions; joint appointments of informal and formal supporters; creating or maintaining circles of supporters, and training and building capacity of supporters more generally.

It is too early in the development of supported decision-making programs and there is too little evidence about their implementation across diverse groups, sectors and institutional arrangements to be prescriptive about its form. There should be continuing room for innovation and for evidence to be gathered about what works, in what contexts, for whom. Nevertheless, all developments should be driven by the application of universal principles of supported decision-making.

3.4 Conclusion

A framework for supported decision-making should recognise the diversity of people with cognitive disability, not only in the severity and type of impairment, but also their social and cultural characteristics. This is to ensure that decision-making support is provided in culturally appropriate ways, and to identify those who can be compromised in accessing such support due to various forms of disadvantage and marginalisation (which intersect with their disability). Diverse types of programs and practices need to be developed, which follow a shared set of universal supported decision-making principles, but address the different challenges, opportunities, needs and choices of people with disability in their full diversity. In particular, attention must be given to design of program and adaptation of best practice to people from culturally and linguistically diverse backgrounds and First Nations peoples.

In Chapter 2, we recommended as the first element of the Framework: '**Recognising diversity in supported decision-making** – Recognising diversity will ensure that reform of law, policy and initiatives about supported decision-making accounts for the diversity of people with cognitive disability, as well as the diversity of contexts and supporters, and ensure that universal principles are translated into the types of programs and best practice that are appropriate to meeting diverse disability-related support needs, and also diverse social and cultural contexts.'

Recommendation 3 Reform of law, policy and development of initiatives must take account of the diversity of people with cognitive disability, contexts and supporters, decisions, jurisdictions and systems to ensure that universal principles are translated into the types of programs and best practice that are appropriate to meeting diverse disability-related support needs as well as diverse social and cultural contexts.

3.1 Funding priority and specific attention should be given to the design of the suite of measures that aims to further understand how the principles and elements of the supported decision-making framework can be interpreted and applied to culturally and linguistically diverse and First Nations community settings. This should include recognition of informal expressions which expand or refine the intention behind decisions to appoint a supporter or substitute decision-maker and expectations of those supporters.

3.2 It is too early in the development of supported decision-making programs and there is too little evidence about its implementation across diverse groups, sectors and institutional arrangements to be prescriptive about a consistent programmatic type of supported decision-making. There should be continuing room for innovation and for evidence to be gathered about what works, in what contexts, for whom. Nevertheless, all developments should be driven by the application of universal principles of supported decision-making.

Chapter 4. Interrelationship of supported decision-making with other systems

Throughout the literature and our fieldwork there is strong recognition that supported decision-making is not something that stands alone. To improve the lives of people with cognitive disabilities supported decision-making must be connected to or embedded within existing service and legal systems, with different – at times contradictory – traditions of decision support. These include disability services, healthcare, residential aged care, Centrelink and the NDIS, to name a few. Taking a principled approached to supported decision-making also demands reforms that embed supported decision-making within existing substitute decision-making provisions particular to some service systems, such as nominee provisions; legal forward planning instruments such as enduring powers of attorney; and legal systems such as guardianship and administration legislation.

Focus group respondents saw supported decision-making as inextricably intertwined with mainstream and specialist services used by people with cognitive disabilities, and as part of existing institutional frameworks such as guardianship and administration, Offices of the Public Advocate, and regulatory bodies.

> SDM needs to be embedded in ‘the quality and safeguards, the practice standards,’ and other evidence accepted by quality auditors. (Advocate–disability)
>
> Need a culture of supported decision-making embedded in each institutional process and policy. (Advocate–aged care)

Many of the focus group respondents were optimistic that over time cultural change would mean that supported decision-making would become a part of practice no matter what the legal context, service system, decision, or support needs of the person involved. In turn this might reduce the need for dedicated supported decision-making programs:

> Agencies with responsibility for people with disabilities need: a good understanding of decision support; to have proficient practice, and to have a supporter available…the better all the service network, whatever those things are, at supporting decisions, then the less need there is for it [supported decision-making]. (Advocate–disability)

Construction of an all-encompassing framework of supported decision-making demands a broad policy lens that considers how it can fit into other parts of the service and legislative landscape. It also demands a willingness to engage with the many dilemmas and conundrums presented across the whole spectrum of issues. Coalition-building and sharing of initiatives and insights between sectors, and appreciation of the contribution of collective action and discussion by groups such as the Supported Decision-making Network,[119] may all contribute to progress towards that end.

This chapter begins by examining differences across jurisdictions, noting the risks in transplanting supported decision-making approaches and programs from overseas, and of applying a national framework across States and Territories with different systems and legislation. We then examine the diverse traditions of decision-making in specific sectors – healthcare, aged care, NDIS, supported accommodation, the electoral system – exploring the specific challenges and opportunities associated with embedding supported decision-making within each. These are the sectors where research has explored issues of supported decision making and adults although not the only ones where it is likely to be important.[120] Finally, we review substitute decision-making systems, and provisions for appointment of substitute (or in some cases supported) decision makers that exist within some service systems or legal instruments and consider the reforms necessary to fully embed supported decision making within these

4.1 Diverse national and jurisdictional contexts

Australia has a national Commonwealth government and State and Territory governments with States and Territories having different legislative powers to those of the Commonwealth. The Commonwealth government has legislative power and responsibilities for nationwide programs such as the NDIS, Centrelink and Medicare. However, it is the State and Territory governments that legislate and control significant substitute decision-making frameworks such as guardianship, administration, enduring powers of attorney and healthcare decision-making. While commonalities exist in relevant frameworks across States and Territories, there are also significant differences. An understanding of this distribution of legislative and policy making authority is imperative in understanding some of the challenges faced in implementing national supported decision-making schemes in Australia.

The significance of the socio-political context must also be recognised in considering how international supported decision-making initiatives might inform a framework that can be applied in Australia. First, the compatibility (or not) of proposed models with different national sentiments will impact on the prospects of successful implementation. Second, consistent with the principles of co-leadership, proposed programs and policies must reflect the perspectives of people with cognitive disabilities and their supporters in the relevant jurisdiction. Third, in transplanting overseas or cross-jurisdiction models, account must be taken of domestic service systems, resourcing and public expectations. Failure to understand the importance of such features risks failure of policy transplants[121] and missed opportunities to capitalise on the potentially positive role played by synergies of culture in successful policy transfer.[122]

Differences in the matrix of underlying socio-political, funding and governance assumptions of supported decision-making models internationally has been under-explored in the literature. But arguably the differences are quite stark and need to be kept front of mind when considering how different countries have operationalised supported decision-making principles. While admittedly crude, some of those differences are as follows:

- Canada, an early adopter of recognising supported decision-making in legislative schemes across its notoriously very socio-politically diverse provinces, has one of the highest number of different legislative configurations. The western provinces, which tend to value neoliberal principles of small government and self-provision, unsurprisingly have crafted schemes which rely more on civil society and less on government investment and oversight; while the eastern and francophone provinces' legislative schemes reflect greater confidence in and thus reliance on the contribution able to be made by government institutions and regulatory machinery.
- In the US, those states which have initiated supported decision-making legislation have been criticised for adopting with minor variations the lowest cost, most family-empowering and neoliberal of the Canadian models, reflecting the privileging of autonomy rights and neoliberal ideology in the US.[123]
- The Swedish Personal Ombudsman ('PO') Skane which provides a publicly funded supporter/advocate for some people with mental illness, resonates with the more devolved public administration (grounded in principles of subsidiarity and deliberative democracy) and its comparatively greater cost is consistent with the more extensive welfare state services found in Nordic countries.[124]

These approaches reflect well known differences in the ways the broader political context – from Swedish social-democracy to Anglo neoliberalism – shapes the design of social policy programs. It is instructive for instance that Canadian inquiries into updating guardianship laws both by the Ady Report in Alberta[125] and by the Law Commission of Ontario[126] were expressly precluded from making any recommendations entailing increased public expenditure.

The Australian national context shares similarities but also differs from other countries. Australia has some cultural and governance features that are similar to Canada and the US. The Australian welfare system is not as extensive as the Swedish or those in some other European countries, but it does provide a level of social security and publicly funded healthcare higher than that which exists in the US, for example. Anglo neoliberalism is entrenched in Australia, but Australia also has an existing infrastructure of publicly funded tribunals, and of Public Advocates, Public Guardians and Public Trustees which can be used to drive the move to supported decision-making (as discussed in Section 4.3). The shift towards individualised funding in aged care and the NDIS also presents opportunities for supported decision-making (as discussed in Section 4.2.3). Arguably this shift actually demands its introduction, to enable anything approaching an authentic type of 'consumer involvement' in what are very complex systems.[127]

The next section of this chapter turns to the diversity of service systems, sectors and supporters and breadth of approaches to decision making that will need to be captured within a single overarching framework of supported decision-making.

4.2 Diverse sectoral traditions of supported decision-making

Although the pace has varied, supported decision-making has been embraced as an important concept by many service systems and civil society arrangements. The literature and our empirical data clearly demonstrate overarching differences between sectors in thinking about supported decision-making, stemming from their different: decision support traditions; pace in shifting towards a rights perspective; and trajectories of the decision support needs of the people in their sector.

The paradigm shift from capacity-based notions of decision-making to supported decision-making generated by the CRPD remains incomplete in Australia. Those sectors with strong foundations in medical models of health and disability are lagging behind those with more entrenched social models. For example, the shift to rights-based policies generally, and supported decision-making particularly, occurred much earlier and is much stronger in the physical, sensory and intellectual disability sectors than in aged care, health, mental health, and rehabilitation sectors that support people with acquired cognitive disabilities.

The next section summarises these differences by sector and particularly where substitute decision-making is embedded in some of these.

4.2.1 Health and mental health sectors

The health sector includes a wide cross-section of people who require decision support for varying periods of time – long term, temporary or slowly increasing. Supported decision-making is not as well understood in general healthcare contexts, where issues of professional liability are often at the fore, driving risk averse perspectives. In this sector the focus tends to be on capacity rather than rights.

Distinct legislative provisions exist about what constitutes capacity to make informed decisions, and prescribe a hierarchy of substitute decision makers when a person is deemed not to have capacity.[128] This hierarchy applies where the person is unable to decide for themselves, there is no tribunal appointment and the person has no relevant forward planning legal instrument in place (eg, enduring power of guardianship/attorney or advance directive) that nominates a person to act on their behalf. Variously called the 'person responsible', 'medical treatment decision maker', 'health attorney' or 'statutory health attorney',[129] this default authority for substitute decision-making is only triggered by decision-making incapacity and the need for a healthcare decision to be made.

One respondent who was a health professional reflected on the focus on consent rather than a broader understanding of supported decision-making in the health sector:

> I don't think there's enough understanding of the complexities around what supported decision-making actually is. ...certainly, the medical context, my personal take is medical professionals try to boil it down to a consent, a yes/no, a very simple "I need a yes/no answer." And often they look at a substitute decision-maker who can give me the yes/no answer, rather than actually looking at the supportive process of getting multiple views, including the voice of the person who's going to be impacted by that decision…. I think there's definitely some work to be done. (Professional)

This suggests that in the health sector, supported decision-making will be understood with reference to prevalent and influential concepts relating to consent and decision-making capacity.[130] Such an approach may risk falling into binary conceptualisations of supported decision-making, as something that is done 'up to a point', with substitute decision-making 'inevitably' operating if the available supports cannot enable the person to meet conventional thresholds for decision-making capacity.

Mental health services are guided by distinct legislative frameworks and the literature reveals that many countries are grappling with how to implement supported decision-making in the context of these. The tensions with recognising human rights – inherent in compulsory treatment – suggests that fundamental concepts may need to be revisited for compliance with the CRPD requirements.[131]

The importance of educating clinicians who traditionally hold 'power' in relationships with people with mental health conditions has also been identified. It has been suggested that training the next generation of clinicians around the principles and concepts that move away from substitute decision-making towards supported decision-making will be crucial in embedding cultural and practical change in mental health services.[132]

There is potential for clinicians across all health services to adopt the principles of a supported decision-making approach and be more aware of the legal obligations that govern supported decision-making in different jurisdictions. Often those who act in health-related substitute decision-maker roles are unaware of the decision-making principles that they are legally expected to follow. In some jurisdictions these principles squarely place the individual person's (as opposed to the substitute decision-maker's) wishes as relevant to the decision, and some may require that supported decision-making be attempted before substitute decisions are made.[133]

However, supported decision-making may also be met in the health and mental health sectors with resistance in the face of concerns of breaching confidentiality and a 'fall back' on substitute decision-making authority may be seen as the least risky option. Implementation of supported decision-making may also trigger an increase in capacity assessments, given the ready access in the health sector to those with expertise in cognitive assessment. Rather than leading to more transformative changes that understand assessment as a process of identifying a person's support needs, such assessment may be used to decide who can or cannot make a decision.

Other barriers in this context include a 'lack of time, competing clinical work, fragmented care services, inadequate professional collaboration and uncertainty in professional roles in relation to [supported decision-making]'.[134]

Confusion may also exist between the concepts and practice of shared and supported decision-making.[135] Shared decision-making[136] is a common practice in medicine, involving clinicians and patients sharing decisions about patients' treatment, recognising both the clinicians' medical expertise, and the patients' right to self-determination.[137] A key difference is that in supported decision-making the decision is not made jointly with healthcare professionals. However, clinician knowledge of shared decision-making practices could usefully be drawn upon in helping to educate them about supported decision-making.[138]

A recurring theme in the literature is the need for leadership and cultural change, as well as targeted training if supported decision-making is to be understood and practice changes successfully implemented in the healthcare context.[139] Some of this has started to occur in some countries, with the Irish PADMACs study one such initiative focusing on decision-making in acute settings by older patients with cognitive impairments.[140]

4.2.2 Aged care sector

Typically, people in this sector have an increasing need for support which occurs in the context of usually having had a long history of making one's own decisions. While about seventy per cent of people with dementia live in the community, it is estimated the figure is fifty four per cent for those in residential aged care facilities[141] and a further six per cent are estimated to have moderate to severe cognitive impairment from other causes.[142] Sector wide, there is high reliance on substitute decision-making to manage institutional risk[143] and a tendency to prioritise protection over autonomy.[144] Focus group respondents concurred with evidence found in the literature, that capacity remains the primary point of reference for decision-making in the aged care sector, and across the sector there is acceptance about eventual loss of capacity and the need for substitute decision-making when this occurs.

> Lack of knowledge about supported decision-making in aged care generally although advocates might have some understanding. Aged care not really had a rights movement. (Advocate–aged care)

Aged Care Quality Standard 1 recognises that: 'consumers who need support to make decisions are expected to be provided with access to the support they need to make, communicate and take part in decisions that affect their lives'.[145] However very little has been done to implement this. This was recognised by focus group respondents in our field work and the Aged Care Royal Commission which recommended that current laws be redrafted to be consistent with the ALRC National Principles.[146]

There are both practice and structural barriers to provision of supported decision-making for people in residential aged care. Supported decision-making is considered resource intensive and difficult to facilitate,[147] particularly in settings characterised by high turnover of staff who lack time to develop trusting relationships with the people they support.[148] Structural barriers include:

concerns about safety and risk versus duty of care; perceptions that some workers need very explicit directions (which are lacking); entrenched protective cultures, and the lack of involvement of frontline workers in policy development.[149]

As with other sectors, there is a recognised need for staff in residential aged care facilities to be trained in supported decision-making.[150] However, this faces challenges given the high staff turnover which means significant resources have to be committed to basic training with limited attention to non-mandated training.

The Australian Cognitive Decline Partnership Centre developed generic training for aged care staff on supported decision-making.[151] This six-hour training package covers the human rights principles, lived experience examples of people with dementia and their family members using supported decision-making, and a series of case-based exercises to promote a problem-solving approach to providing supported decision-making. The training package was piloted in 2019, and while not yet published, preliminary data from 108 participants indicates a positive view of the content and delivery of the training package. Most suggested the material was relevant to their role and had raised their awareness and understanding (95 per cent agreed or strongly agreed ‘the material presented was relevant to my role’, 97 per cent agreed or strongly agreed ‘my awareness and understanding of supported decision-making has increased’). This indicates a strong appetite for training in this area. However, unless such training is linked to mandatory compliance standards for providers, this may become another training option only accessed by motivated staff.

4.2.3 NDIS

The NDIS is founded on a philosophy of choice and control, allowing participants to choose and design individualised packages of supports. However, commentators have pointed out that adults with cognitive disabilities are disadvantaged under individualised funding models such as this.[152] This was borne out, particularly for people with intellectual disabilities in the initial evaluation of the scheme.[153]

Advocates and academics alike have stressed the importance of supported decision-making for NDIS participants and drawn attention to its omission in the scheme.[154] This has meant heavy reliance on appointment of nominees with powers of substitute decision-making. Little is known, however, about the process of their appointment or their approach to decision making. The NDIA’s recent consultation paper revealed:

> NDIA data from 30 September 2020 shows that about 30 percent of participants have a nominee appointed. This increases significantly for people with cognitive impairment. The data also shows differences between location and disability types. In the Northern Territory, nominees are used by 31% of participants with acquired brain injury, autism spectrum disorder, cerebral palsy, Down syndrome and intellectual disability. In Western Australia, it is 50% for the same group. Participants with Down syndrome are most likely to have a nominee (69%), while 43% of participants with intellectual disability have a nominee. This information shows that there are likely to be inconsistencies in the way nominees are appointed by the Agency.[155]

Very soon after its formation the National Disability Insurance Agency ('NDIA') Intellectual Disability Reference Group raised supported decision-making with the Commonwealth Government.[156] In recognition of these concerns in 2018 the Australian Government Department of Social Services funded small pilot supported decision-making programs in each State and Territory that targeted people potentially eligible for the NDIS who were socially isolated and without decision support. The mandate of these programs was confined to supported decision-making for initial rather than ongoing access to the NDIS. These programs were evaluated internally but evaluation reports are not publicly available.

A 2019 review of the NDIS legislation identified supported decision-making as an outstanding policy matter and recommended its inclusion in the forward work plan of the Disability Reform Council. In making this recommendation the review also called for a review of NDIS nominee provisions and noted the intersections between the NDIS and State and Territory guardianship legislation.[157]

In 2021, the NDIA began a project on supported decision-making by consulting widely on a discussion paper.[158] The report of the consultation demonstrated the importance that NDIS participants, their families, service providers and advocates attached to inclusion of supported decision-making in the NDIS. A co-design process is currently underway to design a policy and implementation plan for supported decision-making.[159] As yet there is no commitment to funding. To date, empirical research focused directly on supported decision-making in the NDIS has been absent.

Compounding the absence of a formal supported decision-making scheme, current NDIS policy does not allow funding of supported decision-making in a participant's package,[160] other than one off funding to establish a microboard (see discussion at Sections 5.3 and 8.3.1). The focus groups did not engage in the detail of embedding supported decision-making into the range of service systems used by people with cognitive disabilities. They did note however, that the shift to individualised programs in the NDIS (and aged care and the various traffic injury compensation schemes) meant there were already relatively simple mechanisms in place to allocate funding to remunerate decision supporters. An individual could, for example, be allowed to purchase supported decision-services, as part of a package, from established providers in the event that no other unpaid support can be accessed.

> Need to include supported decision-making in NDIS plan so that adults can purchase support.…Could also include funding in aged care packages. (Advocate – generic)

Respondents drew attention to other design and implementation issues in the NDIS which they thought created barriers to implementing a supported decision making framework. These included: lack of any capacity building for supporters about supported decision-making; lack of any monitoring of NDIS nominees by the NDIA and the associated absence of oversight by NDIS planning or Local Area Coordination staff of the quality of informal supported decision-making for participants. We note however, some of these issues have been the focus of recent policy work by the NDIA.

As well as these broader issues, there are several more nuanced aspects of NDIS design that create potential barriers to supported decision-making implementation. One is the requirement for NDIS participants to enter into formal contracts with service providers, and the legal frameworks that prevent some people with cognitive impairments from doing so – driving a push for appointment of substitute decision-makers. This issue was explored in depth by the Office of the Public Advocate (Vic) and is associated with the exponential rise in guardianship applications for people with intellectual disabilities.[161] It was also raised by focus group respondents, who noted the:

> …competing forces at play, but we see the human rights developments that are increasing the call for supported decision-making in opposition to substitute. But then, we have service developments down into disability spaces, they are increasingly seeking decision-making authority, which led towards the substitute decision-making, which is problematic. (Advocate–generic)

A second NDIS design issue identified by respondents was the process-driven nature of the planning system and the time constraints imposed on the Local Area Coordination role.

> NDIS doesn't really allow Local Area Coordinators to do supported decision-making because we are required to follow a sequence of events in a planning process that isn't sympathetic to complex experience…supported decision-making requires a long time to establish trust and rapport and the NDIA doesn't allow for that time…. They have done a 'time motion study' and estimate planning takes 4 to 6 hours – this doesn't allow for people with nuanced communication needs. (Service provider)

Related to NDIS planning process were the relationships between those who may be involved in planning processes for a participant, who may include a formal nominee as well as other supporters.

> Needs to be a change in the planning process and more clarity about nominees. There needs to be a clear distinction between people involved in the planning process with authority to make decisions, and people who are supporting decision-making. This difference is not clear at the moment. (Service provider for NDIS Local Area Coordination)

4.2.4 Supported accommodation for people with disabilities

People with all types of disabilities live in various forms of supported accommodation. In these settings, there are likely to be uneven power relationships between residents and staff, who are also decision supporters especially for day-to-day matters. Residents in smaller, community-based supported accommodation settings are better supported to make everyday decisions than their counterparts in larger congregate residential settings.[162] However, even in smaller settings there is significant variation in the quality of support, and in some services staff make decisions about everyday activities reflecting their own preferences, or what they perceive as beneficial for a group of residents, rather than any individual resident's will and preferences.[163]

For some residents, staff or professionals from the supported accommodation service may be their only source of decision support. Others may be able to draw on people from outside the service such as family, friends or support coordinators.

The barriers to staff providing effective supported decision-making in these settings are similar to those in aged care. High staff turnover leads to challenges in developing trusting relationships.[164] In addition, low staff ratios or chronic understaffing may mean staff do not have the time to provide support for decision-making, and the tensions between respect for individual autonomy and duty of care may lead staff to err on the side of protection.[165] As with other sectors, there is a need for education and training of staff who may be called upon to act as supporters – whether acting informally or formally appointed.

4.2.5 The electoral system

Article 29 CRPD provides that people with disabilities have a right to participate in political life including a right to vote. The effect of article 12 of the CRPD is that their legal capacity to vote must be recognised. In many countries the appointment of a guardian may mean that an adult no longer has a right or opportunity to vote.[166] While this is not the case in Australia, the *Commonwealth Electoral Act 1918* (Cth) nevertheless provides that a person of ‘unsound mind’ who is ‘incapable of understanding the nature and significance of enrolment or voting’ is not entitled to vote.[167] There is minimal oversight of this provision, which is inconsistently applied and has been widely criticised by disability advocates, leading to recommendations for amendment together with research on practical barriers to voting for adults with cognitive disabilities.[168]

The ALRC Report recommended that electoral legislation be amended to repeal the ‘unsound mind’ carve-out described above and provide instead that it would be a ‘valid and sufficient reason’ for failing to vote if an adult does not have functional decision-making capacity. The effect of this would be that an adult with cognitive disability would have the right to vote; but would not be penalised for failing to do so if they did not have the capacity to understand, retain or weigh the relevant information or did not have the capacity to communicate their vote.[169] The ALRC Report further recommended that returning officers should be provided with training on the National Decision Making Principles, and that an adult may be permitted to choose someone to assist them with voting.[170] Bigby et al conducted research on barriers to and facilitators of voting in Australia, with recommendations including that electoral commissions and non-government bodies explore strategies to produce and disseminate accessible information about public affairs.[171]

Very little research has been conducted in Australia on how supported decision-making may assist people with cognitive disabilities to vote or participate in political life. There is, however, a growing international body of research and advocacy about political participation of people with intellectual disabilities, particularly in the UK and Scandinavian countries.[172] Denial of the right to vote significantly undermines the right to autonomy that supported decision-making seeks to further. We support the recommendation of the ALRC that the ‘unsound mind’ provisions in Australian electoral legislation be repealed.

4.2.6 Financial systems

Substitute decision-making has figured much more prominently in financial systems than supported decision-making. This has been driven by the reality that money does not move itself and the financial system requires formal authority for others to make transactions on someone else's behalf. Substitute decision-making is very common for financial matters, reflecting a range of mechanisms for the appointment of substitute decision makers. First, variously named tribunals in each State and Territory can appoint financial administrators for those who lack decision-making capacity and need a decision maker. Second, forward planning legal instruments allow people with capacity to appoint an enduring power of attorney to act for them in the future should they lose decision-making capacity. (These two types of appointment are discussed in Section 4.3 below as they are similar to and often occur in conjunction with appointment of substitute decision makers for other aspects of a person's life). Third, Centrelink allows a nominee to be appointed to receive and administer a person's social security payment, and NDIS plan nominees, discussed in the previous section, also hold power to act for the person in financial matters.

Centrelink nominee provisions. The majority of people with cognitive disability are reliant on social security pensions or benefits for their sole or main source of income, and their assets and property holdings are likely to be small. Control over their finances or support to continue to manage expenditure according to their will and preferences is likely therefore to hinge on Centrelink options for control and management of their social security payments. Two options are available to the person, both called nominees. A payment nominee can make substitute decisions for the person, and a correspondence nominee is empowered to act as a channel of communication between the person and Centrelink.

Reforms to nominee provisions in 2002 significantly tightened the consent and capacity requirements for nominee appointments, and the 'trustee/fiduciary' and record keeping obligations of payment nominees. The terminology of the two powers remains unaltered despite ALRC recommendations for amendment to bring the legislation more closely in line with CRPD principles. Since 2014 Centrelink has however reduced some of the pressure to make nominee appointments by introducing two non-legislative options: the authorisation of a 'person authorised to enquire' and a 'person authorised to update' information.[173] The differences between the four types of Centrelink appointments are set out in the following table (Table 2).

Table 2. Four types of Centrelink decision support appointments

Your authorised persons or organisations can:	Persons permitted to inquire	Persons permitted to update	Correspondence nominee	Payment nominee
Ask questions about your payments or service	Yes	Yes	Yes	Yes
Tell us about changes to your circumstances	No	Yes	Yes	No
Respond to requests for information	No	Yes	Yes	No
Come to appointments with you or, if appropriate, on your behalf	No	No	Yes	No
Complete and sign forms and statements	No	No	Yes	No
Get copies of your letters	No	No	Yes	No
Get your Centrelink payments and use them only for your benefit	No	No	No	Yes
View and update your information online	No	No	Yes	Yes
Claim payments and services for you	No	No	Yes	No

Source: Services Australia Data and Analytics Division, 10 June 2022

Total numbers of appointments at the end of each calendar year are reported in Table 3.

Table 3. Total numbers of Centrelink decision support appointments

As at Dec	Payment and Correspondence Nominee	Correspondence Nominee	Payment Nominee	Person Permitted to Enquire	Person Permitted to Update
2013	105,179	814,111	42,198	6,599,860	0
2014	110,967	897,931	41,814	6,742,300	0
2015	116,805	978,996	42,507	6,851,824	0
2016	122,989	1,050,505	43,751	6,982,420	0
2017	125,770	1,105,652	43,136	7,064,873	0
2018	128,555	1,155,768	42,686	7,119,653	0
2019	131,120	1,197,434	42,135	7,172,366	0
2020	131,732	1,230,252	37,741	7,380,900	223
2021	130,527	1,274,290	33,726	7,435,084	7,940

Source: Services Australia Data and Analytics Division, 10 June 2022

From 2013 to 2021, the number of people subject to a correspondence nominee alone increased by 460,179 (56%), while those subject to a payment nominee alone declined by 8,436 (20%). These trends, along with the rise of 835,224 (13%) in the numbers of people 'permitted to enquire' and the very recent growth in 2021 in those 'permitted to update', suggest declining reliance on substitute decision-making. This is because correspondence nominees are effectively only empowered to serve as a channel of communication.

However, even accounting for demographic ageing and population growth (a 10.4% increase), this decline in substitute decision-making is partially offset by increases elsewhere. There has been a 25,348 (24%) increase in the number of people subject to both a payment nominee and a correspondence nominee appointment (130,527 in December 2021). This is significantly higher than the range of 32,000-82,000 estimated in Creyke's 1990s study.[174] The significance of this is that payment nominees are substitute decision-makers, and neither of the two types of nominee appointments oblige appointees to be directed by the person's will and preferences. There are also few safeguards surrounding such instruments around for example, when a person may become unwilling to continue to act, or when they abuse or neglect the trust placed in them.

4.3 Substitute decision-making systems

Substitute decision-making systems include the variously named Offices of Public Advocates, Public Guardians, Public Trustees and tribunals. Forward planning instruments such as enduring powers of attorney and advance care directives also allow for substitute decision making, as do Centrelink and NDIS nominee provisions already discussed. Table 4 summarises substitute decision making roles that exist within various legal and services systems in Australian. Focus group respondents saw supported decision-making as inextricably intertwined with these.

Table 4. Summary of existing substitute decision-making roles in Australia

Name	Role / description)
Centrelink correspondence nominee	A role recognised by Centrelink to act as a channel of communication on a person's behalf but cannot receive Centrelink payments.
Centrelink payment nominee	A role recognised by Centrelink that can receive Centrelink payments and exercise substitute decision-making authority to use them for the benefit of the person.
NDIS nominee	A role recognised by the NDIA that also contains authority to act as a substitute decision-maker on behalf of an NDIS participant for NDIS funding and other decisions.
Guardian	A substitute decision-maker appointed by a State or Territory administrative tribunal for a person who lacks decision-making capacity where there is a need for a personal decision to be made. Decision-making authority can be limited to certain decisions or types of decisions.
Administrator	A substitute decision-maker appointed by a State or Territory administrative tribunal for a person who lacks decision-making capacity where there is a need for a financial decision to be made. Decision-making authority can be limited to certain decisions or types of decisions.
'Default substitute decision-maker' for health decisions (known in different jurisdictions as 'person responsible' 'medical treatment decision maker', 'health attorney' or 'statutory health attorney)	A substitute decision-maker for healthcare decisions where a person is unable to make a healthcare decision for themselves, and no other substitute decision-maker has been appointed by a tribunal or the person (via a forward planning legal instrument) before the person lost the capacity to make decisions.

Name	Role / description)
Enduring attorneys and guardian	A substitute decision-maker previously selected by the person (when the person had the ability to make decisions) who is given authority to act on behalf of the person at a time when they no longer have the capacity to make decisions. Decision-making authority can be limited to certain decisions or types of decisions.

Guardianship and Administration. Guardianship tribunals in all States and Territories can appoint a public office or private citizen as a substitute decision-maker to make decisions for a person on personal matters, as a guardian of last resort.[175] The public offices are called the Public Guardian, or in Victoria, South Australia and Western Australia, the Public Advocate. Guardianship tribunals in all States and Territories can also appoint a Public Trustee or private citizen as a substitute decision-maker for financial matters. In the Northern Territory the Office of the Public Guardian can be appointed for both personal and financial matters.

Offices of Public Guardians and Public Advocates. Functions of these offices, in addition to appointments as guardians of last resort, vary significantly between jurisdictions and can include: investigating complaints of abuse and neglect of people with cognitive disabilities, systemic advocacy, individual advocacy or community visitor programs for supported accommodation. Notably, Victoria, Queensland and the ACT have additional independent Offices of the Public Advocate charged with systemic advocacy responsibilities. Offices in all jurisdictions have responsibility for educating the community on their own responsibilities and on guardianship and administration systems more broadly. Importantly, they can receive complaints about possible wrongful conduct by substitute decision-makers – regardless of whether they have been privately appointed by the person or by a tribunal.

These variously named offices have already expanded their remit to include advocating for, researching and educating the public about supported decision-making. Together with guardianship tribunals these offices could serve as important gatekeepers in ensuring that guardianship orders are made only when they are the least restrictive alternative and where all informal (or any formal) supported decision-making options have been exhausted. They could also help to ensure that supported decision-making choices and principles are maximised even when substitute decision-making powers are conferred, through careful choice of appointees and crafting of orders.[176] Even in the absence of a citizen willing to accept appointment as guardian or administrator, research has demonstrated that orders empowering the Public Trustee, Public Guardian or Public Advocate can be administered in ways which maximise autonomy and respect for principles of supported decision-making.[177]

4.3.1 Reform of guardianship and financial administration to embed supported decision-making

Whenever substitute decision-makers are appointed and their authority applied, a person's legal decision-making rights are supplanted. While terminology and details differ between jurisdictions, the legal schemes are largely comparable. However, significant differences exist with respect to formal legal recognition of supported decision-making. Most States and Territories do not explicitly recognise a legal form of supported decision-making.

An important component of our proposed framework is the reform of Australia's adult guardianship and financial administration laws to align them as far as possible with supported decision-making principles. In some jurisdictions reforms have incorporated aspects of supported decision-making into guardianship regimes. For example, supported decision-making principles have been embedded into the decision-making principles of guardianship legislation in the Northern Territory and in Queensland.[178] In these jurisdictions, the legislation mandates that supported decision-making be attempted before substitute decision-making. While relatively minor legislative amendments, these reforms have had an impact, particularly on statutory bodies which represent many people with cognitive disabilities. This is evident for example in the Queensland Public Trustee which has embedded into its operations training for all staff in supported decision-making to ensure compliance with the Queensland decision-making principles.[179]

The Australian, NSW and Victorian law reform commissions, among others, have set out detailed and more ambitious reform blueprints. A suite of reforms in Victoria, formally recognise a legal supporter role.[180] These reforms allow self-appointment of supporters; grant the Victorian Civil and Administrative Tribunal (VCAT) power to appoint 'supportive guardians' and/or 'supportive administrators'; require consideration of such appointments before appointing a substitute decision-maker (guardian or administrator) and replace a 'best interests' with a 'will and preferences' test for making an appointment. Somewhat surprisingly however, reportedly no supporter appointments have been made by VCAT since the reforms came into operation. One reason for this may be the gravity of the personal circumstances precipitating the VCAT application and the exhaustion of previous informal or other support mean that supported decision-making is not viable. However, we believe that two serious design flaws in the legislation are a major contributor. These are that the requirement that the person consent to appointment of a supporter; and that the VCAT appointment restore a person's full decision-making ability (i.e., with support the person meets a threshold of decision-making capacity).

In relation to the requirement for consent, VCAT has found, in all of the more than 50 reported decisions, either the person lacked the capacity to consent to appointment of a supporter, or (in a very few) that the person declined to give consent.[181] This strict requirement of consent meant that VCAT was obliged to appoint a substitute decision-maker without any need for the person's consent. The second apparent design flaw is that the insistence on restoring full decision-making ability does not reflect a principled approach to supported decision-making. It sets a high bar that in practice appears to be interpreted as restoration of capacity across a very broad area of decision making. In our view both these design features should be reconsidered.

However, important as it may be, reforming existing guardianship and financial administration arrangements will only impact on a small proportion of the population of potential beneficiaries of supported decision-making. Modelling by the Victorian Law Reform Commission[182] revealed that guardianship only caters for about 2 per cent of all people with a significant cognitive impairment. Unlike in the US, Australian guardianship tribunals do not countenance a 'pipeline' of mass transitioning of young people with intellectual disabilities into applications for guardianship on their 18th birthday.[183] They also largely deflect pressure from residential aged care or disability providers for guardianship as a 'condition' of entry.[184] Concentrating on reform of guardianship will miss the vast majority of people who will only ever encounter informal arrangements made by their family friends or associates that represent substitute decision-making, or the exercise of substitute decision-making under any enduring powers of attorney they may have signed.

While the proposed reform of guardianship and administration described above is warranted, we suggest that initiatives for supported decision-making that target substitute decision-making under other frameworks should be more heavily prioritised. This includes reform of healthcare, Centrelink and NDIS nominee provisions (considered next), as well as the informal sector and the middle of life decisions that people frequently make in executing some form of private forward planning instrument in anticipation of future life contingencies (discussed in Chapter 8).

4.3.2 Reform of health sector, Centrelink and NDIS provisions that authorise substitute decision-making

Laws other than guardianship and administration that authorise substitute decision-making need attention. A comprehensive reform agenda should reflect the scale and significance of potential impact of reform.

Default substitute decision makers. In terms of the widest potential impact on all Australians, the most pervasive legal domain is in the health sector whereas discussed above, laws set down a 'list order' of 'default substitute decision-makers' automatically authorised to make health decisions.[185] Every Australian adult may potentially use this. The relevant State or Territory legislation should, if not already in these terms, be reformed to ensure that decisions made by the default decision-maker accord with the will and preferences of the person, are a last resort and for the shortest possible time.[186]

Private forward planning legal instruments. In terms of direct impact on the largest number of Australians, the most significant set of laws are those governing private forward planning appointments of substitute decision-makers such as enduring powers of attorney for guardianship or administration or separate enduring health powers (including under advance directives).[187] There are no accurate figures on the number of such instruments. However, extrapolation from surveys showing that up to 30 percent of solicitors draw up enduring powers with a will, suggests that enduring powers of administration, guardianship and health decision-making cover in excess of 3 million people.[188] Enduring powers of attorney were designed for people without cognitive impairments who were contemplating a future need for a decision support (such as due to a future dementia, acquired brain injury or mental illness). Under existing legislation, the power granted under forward planning legal instruments is that of substitute decision-making. These instruments may reflect a principled approach to decision-making principles in the very limited sense that they already enable nomination of someone chosen by the person. However, they can be significantly improved by a requirement that decisions be guided by a person's will and preferences and provision for the opportunity to record a statement about the person's will and preferences at the time of appointment.

Further discussion and recommendations for enabling forward planning – including enacting the option of appointing a supporter or enduring supporter – are discussed in Chapter 8.

Centrelink and NDIS nominees. Reform of the Centrelink payment nominee system is urgent, because of the vulnerability of the population.[189] Some view these powers as 'guardianship lite' and of marginal significance for change. In our view this is not the case, given that large numbers of Australians with cognitive disability who are solely or mainly reliant on social security incomes and are handing control of their payment to a substitute decision-maker, effectively meaning the payment nominee controls most of their life.

As indicted in Section 4.2.6 above, the number of appointments of Centrelink nominees is increasing. The scale and impact of these mechanisms of substitute decision-making, dwarf guardianship and administration. Data for the 2021 calendar year reveals a total of 164,253 people subject either only to a payment nominee appointment (33,726) or to a combination of both payment nominee and correspondence nominee appointments.[190] That total figure for Centrelink payment nominees is far greater than the rough estimate of 14,000 adults under guardianship or the 47,000 adults whose affairs are managed by the public trustee.[191] By way of comparison, the flow of new entrants to guardianship and administration is less than 20,000 annually.[192]

There is a similar urgency for reform of NDIS nominees given the principles of the scheme, the high proportion of participants for whom a nominee is appointed (30%) and the absence of any real understanding of the processes of appointment or approach of nominees. Centrelink payment nominee, correspondence nominee and associated arrangements and NDIS nominee arrangements should all be reformed in line with the principles of supported decision-making. Similar to proposals for reform of 'default substitute decision-makers' in the health context, and enduring powers of attorney, appointees should be required to put the will and preferences of the person they support at the centre of all decisions.

4.3.3 Summary

Contrary to much popular and academic thinking, a significant arena for reform of substitute decision-making systems is not just that of guardianship and administration. Of some urgency is reform of Centrelink and NDIS nominee systems, and measures to encourage execution of supporter appointments instead of (or at least in conjunctions with) private forward planning legal instruments such as enduring powers of attorney. This reform would impact the next largest group of potential beneficiaries of a shift to supported decision-making. If effective, it also would over coming decades, radically alter composition of the 'pipeline' of people whose future lives will only ever be impacted by the coming into force of such instruments.

Guardianship reform is clearly important for those people currently subject to guardianship or administration orders who may benefit from supported decision-making. It is also important for reasons of principle such as elevating will and preferences in place of best interests paternalism, and because enactment of supported decision-making in such peak legislation provides symbolic educative guidance. However, other systems also need to be a focus of reform.

4.4 Conclusion

The universal principles of supported decision-making need to be embedded and operationalised within the range of existing systems with which people with cognitive disability interact in their everyday lives, across the ‘formal’ and ‘informal’ sectors, and from ‘mainstream’ systems such as healthcare, electoral and financial systems, to ‘specialist’ service systems, such as aged care, NDIS, supported accommodation, and guardianship administration. For some people interaction with these systems and the need for supported decision-making will only be intermittent or occur for a small fraction of their life course. Others however, particularly those with lifelong disability, interact frequently with multiple systems across many aspects of their lives for much of their life course and their continuing need for supported decision-making means its availability or otherwise has a significant and continuing impact on their quality of life. Reforming these systems presents unique challenges, including established traditions of substitute decision-making. But each also presents opportunities, such as the individualised approaches emerging in the NDIS, and a range of infrastructures and resources that can be used to promote and enhance supported decision-making (including those very same infrastructures that have traditionally promoted substitute decision-making, such as guardianship and administration systems).

In Chapter 2, we recommended as the second element of the Framework: ‘**Interrelationship of supported decision-making with other systems** - Recognising the interrelationship of supported decision-making with other systems acknowledges that it cannot stand alone and must be embedded in and connected to existing service systems with different institutional and legislative frameworks. A broad perspective should be adopted that considers for example, how statutory supported decision-making can fit into other parts of the policy and legislative landscape’.

Recommendation 4 The interrelationships of supported decision-making with other formal systems and informal spheres of life means that supported decision-making cannot stand alone and must be embedded in and connected to existing systems with different institutional and legislative frameworks.

4.1 Context-specific supported decision-making action plans should be produced for different service systems and institutional settings, each outlining a portfolio of legislative and non-legislative measures to improve quality and take up of supported decision-making in that context, while adhering to a shared agreed set of universal principles.

4.2 All ‘unsound mind’ provisions in Australian electoral law should be repealed, and strategies put in place to ensure all people with cognitive disabilities are enrolled to vote but not penalised if they choose not to.

4.3 State or Territory laws enabling ‘default’ substitute decision-makers for healthcare decisions should be reformed so that substitute decisions made by default substitute decision-makers accord with a principled approach, have the will and preferences of the person at the centre, are a last resort and for the shortest possible time.

4.4 State or Territory laws allowing self-appointment of substitute decision-makers with authority to make decisions once a person is no longer able to make decisions should be reformed to reflect a principled approach to supported decision-making and ensure that decisions made by the substitute decision-maker are in accordance with the will and preferences of the person.

4.5 Centrelink payment nominee, correspondence nominee and associated arrangements should be reformed to reflect a principled approach to supported decision-making and ensure that decisions made by the substitute decision-maker are in accordance with the will and preferences of the person.

4.6 NDIS nominee provisions should be reformed to reflect a principled approach to supported decision-making and ensure that decisions made by the substitute decision-maker are in accordance with the will and preferences of the person.

4.7 State and Territory guardianship and administration laws should be reformed in accordance with a principled approach to supported decision-making. New statutory tribunal appointed supporter roles (similar to Victoria) should be implemented but consideration given to the need for a person to consent to tribunal appointed supporters or for decision-making ability to be restored as a condition of appointment.

4.8 Collection of monitoring data on trends in various types of support, nominee, attorney/guardianship powers should be collated, and surveys undertaken to obtain data about informal arrangements. The Australian Institute of Health and Welfare may be an appropriate body to have carriage of this responsibility.

Chapter 5. Best practice and ethical supported decision-making

The ALRC principles and guidelines operate at a high level of generality and conceal many of the dilemmas identified in research that confront decision supporters about practice. The literature identifies many of these challenges and the heavy emotional load decision supporters face in maintaining a continual focus on supported decision-making and conforming to the ALRC's support guidelines.[193] This was captured by one supporter in Bigby et al's study who likened supported decision-making to 'twirling plates on a stick' as they continually juggled 'rights, risks and practicalities'.[194] It is clear for example, that supporters do consider likely outcomes of a person's decision where these pose a significant risk of harm to the person or others, and research indicates such contemplation may lead to subtly influencing or narrowing the parameters of the decision and the options considered to shift towards a less risky outcome.[195]

Universal principles do not give sufficient guidance for supporters to grapple with the everyday practice dilemmas they confront. This is especially the case in the disability and aged care systems where most paid supporters are low paid direct support workers rather than highly trained and tertiary educated professionals. Outside of service systems, supporters are mostly unpaid family, friends or associates with little or no training in supported decision-making. Fidelity to principle at the operational and practice levels calls for greater explication and guidance about best practice and the development of nuanced skills for supporters.

The term 'best practice' refers to tried and tested or evidence informed practices or interventions that are accepted as more effective than other known practices in achieving desired outcomes, while maintaining fidelity to underpinning values and principles. The term 'best practice' has been the subject of debate and criticism, not least because 'best' is not necessarily 'good' and what is best in one context might not be so in another. Nevertheless, it is a useful tool for sharing of knowledge – and at times detailed guidance and techniques – within communities of practice, allowing replication, adaptation and ongoing striving for improvement.[196]

5.1 Conditions, skills and knowledge that underpin best practice

Focus group respondents identified best practice supported decision-making as a key element of a supported decision-making framework. They thought an understanding of best practice should guide support practice and help ensure its quality by setting out principles, processes, skills and conditions for good practice. They also endorsedthe importance of evidence in developing and testing models of practice.

> We need key practice elements identified by researchers. (Advocate-generic)
>
> Need a framework and process that people can follow. (Advocate–disability)

The literature recognises – as did the focus group respondents – that there are some common core elements of best practice supported decision-making despite the diverse contexts of practice and the diversity of the people supported. These include: knowing the person well;[197] understanding the person's impairment, health conditions, social and service contexts;[198] having an attitude that the person is capable of participating in decision-making, and being committed to creating opportunities for decision-making.[199]

> A 'big ask' for an 'advocate' or supporter to get across all systems -guardianship, housing, child protection – but principles remain the same and the supporter needs to be working in the same framework. (Advocate–disability)
>
> The type of support will be different across individuals, although similar in trying to promote autonomy. (Advocate–carers)
>
> Need to use language that is inclusive and is about expressing will and preference. Actual strategies and tasks and activities may be very different depending on how the person expresses their will and preference. (Service provider)

Similarly, common support strategies were identified in the literature and by focus group respondents. The most common in the literature were: the need to take time and not rush;[200] to consider communication needs and tailor communication to the person;[201] and to give options from which the supported person might choose.[202] Focus group respondents saw best practice supported decision-making as skilled, complex and often intense, and above all else required time to be done well.

> Three people in my house can't use an iPad or phone – so need to have a worker who 'notices things in that person, notices little things that they enjoy…' or activities they do. Two of them have parents involved but they can't speak to let their parents know they're not being supported to make decisions. Sometimes you just need to observe, take the time. (Self–advocate)
>
> Takes time ultimately to provide supported decision-making to an individual. It is based on trust and relationship, so even if you have the skills and go into supported decision-making as a profession, with tools for communication support and getting to know the person it takes time. Structures in place in the different sectors need to allow for it. (Service provider)
>
> ...it was extra time, and questioning me in all different ways to make sure I understood it. (Self-advocate)

Emphasising the need to allow supporters sufficient time for good decision support, one respondent drew attention to the lack of resources and time limiting ability to engage with the person, and can be, as they said, disastrous.

> So, the risk is that in trying to do supported decision-making in haste, or at arm's length, or shortcuts or whatever, there may certainly be cases where that's manageable, but certainly the clients we've dealt with, that would be a disaster. (Advocate–disability)

5.2 Supported decision-making practice frameworks, tools, training

The literature review identified a range of generic or disability specific guides to practice, tools and training programs.[203] Some of these were undergoing evaluation or had been evaluated through pilot programs. However, most had little by way of publicly reported evidence demonstrating their effectiveness in improving support for decision-making for people with cognitive disabilities. The two with the strongest evidence for impact on the practice of supporters were the La Trobe Framework and associated training materials,[204] and a training package on Supported decision-making for people with dementia.[205]

The La Trobe Framework is based on a program of research about supported decision-making practice with people with intellectual disabilities and people with acquired brain injuries. It recognises some of the differences between supporting these two groups. For example, for many people with ABI they find it easy to talk about themselves compared with people with intellectual disabilities many of whom experience difficulties in expressing their support needs. In the case of people with ABI there is also a particular impact on supporters of knowing a person before and after an accident that supporters of people with lifelong disabilities do not experience. The La Trobe Framework is also one of the very few programs of research that has explored supported decision-making practice with people with more severe intellectual disabilities and evaluated the impact of training on supporters of that group. The research on which it is based and the research about its effectiveness has been published in both peer review and the grey literature over a period of 10 years.[206]

The Supported decision-making for people with dementia package was based on a three-year project with people with dementia, professionals and family members and other research about supported decision-making led by Sinclair. Both models have similar elements, but they also demonstrate the differences that arise in practice with different groups, particularly between people with a stable cognitive disability as opposed to an increasing need for support. For this latter group, supporters have to manage the balance between 'eliciting and acknowledging the person's current will and preferences, while also respecting their previously established will and preference' which is not something supporters of people with stable support needs have to consider.[207]

These two practice frameworks were also the ones most commonly mentioned by focus group respondents giving some indication of their widespread dissemination and impact on practice in Australia. Another indication of their impact is that almost all of the key elements that focus group respondents felt should be included in best practice supported decision-making are included in both of these research-based frameworks. We summarise below the key elements described by focus group respondents (see Appendix A for descriptions of the research-based frameworks).[208]

Knowing the person and tailoring communication.

This encompasses understanding how a person communicates, processes and understands information, and their family, social and service contexts.

> Clearly, you need to start with knowing the person with disability and getting to know how they communicate and express their will and preference. (Professional)

> …getting to know the person, getting to know their will and preference. Getting to understand the context that they live in. What their environment is. Who their important people are? All of those things are the background to really good, supported decision-making. … being able to understand how someone wants their choices presented to them…are they someone that is happy to have a conversation on the fly? Are they someone that wants to have a conversation, but then given a couple of days to think about it before they come back? Are they someone that needs that translated into some kind of collateral that they can hold on to, so that they can look at words or images in order to process? (Service provider)

Expanding and exploring options.

Supporting a person to consider their preferences about options for a decision was seen as much more complex than simply asking or giving them information. Rather it was seen as a proactive, and creative process whereby options were actively explored, and different strategies were used to elicit and understand a person's preferences.

> As supporters, we have an obligation to expand a person's decision-making context, environment so that we are not consigning someone to the same ideas, options and opportunities. (Service provider)

Ensuring a person had understood what might be possible or that the supporter had interpreted their response correctly was an important part of this process.

> [the supporter] has to point out all the pros and cons, and what could happen to you, and can they sell from under you and all that sort of thing… that was critical … it was extra time and questioning me in all different ways to make sure I understood it, and open questions for me to come back to him to basically mirror what he said and understand it. (Self-advocate)

> … then the person who's working as the decision supporter needs to have a way of acknowledging and reflecting back their understanding of that will and preference, so that then that can be supported to be conveyed in whatever circumstance that needs to occur. (Professional)

Enabling risk.

Directly addressing the risks that might be associated with a decision was seen as important, and if necessary, finding strategies to mitigate or enable risk.

> Any framework needs to address the issue of harm – i.e., What decisions is it appropriate to support and which not to support. (Advocate–generic)

Transparency.

Being transparent about support processes and documenting the various steps used or options considered were seen as part of best practice, both in terms of accountability and reflexivity. Indeed, some respondents saw the processes of support as more important than outcomes.

> Transparency's important because I guess there's so many people involved in the lives of people with disability... who's giving her what advice and where that advice has come from. (Family–disability)

> …undertaking a process without an outcome in mind is a safeguard against undue influence. (Service provider)

Listening and communication skills.

There was unanimous agreement that all decision supporters needed good listening and communication skills. As one self-advocate said about the skills of a supporter she had valued, they

> had very good people skills and very good listening skills, which made a really big difference, and to have someone like that I think is really important, and I think you have to shop around for it. (Self-advocate)

Self-reflexivity.

Awareness of their own potential to influence on the person they supported, the ease with which they might be manipulated, and self-reflection were seen to be skills needed by supporters.

> And the person who is providing the decision support needs to have some form of reflective behaviour that is – able to elicit any understandings of bias or where their views may, in fact, be getting in the way of conveying the person's will and preference. (Professional)

> Supporters need to be trained and understand 'influence and subtle coercion,' and how to be objective and neutral. (Advocate-generic)

Tools such as checklists derived from practice frameworks were seen as useful in assisting supporters to identify processes they had used.

> …this is the way we do things; we sit down around the table all together, all of the parties, go through this checklist, which is all from the person's perspective like 'did you want a second opinion? Have you had the opportunity to get a second opinion?' and then based on that checklist, you have like a 'this is how we're going to move forward', like a bit of an agreement, a bit of an action plan.' (Family–disability)

5.3 Supporter relationships

The literature points to various aspects of the relationship between a supporter and the person they support which are important to operationalising supported decision-making principles and are common across all contexts. These include that: supporters should be independent of the service system which the person uses; supporters should be chosen by the person; a person should have more than one supporter and determine the roles each plays, and there should be a trusting relationship between supporters and the person they support.[209] Notably, all of these features were raised by focus group participants from their own experiences.

The independence of paid supporters from service systems was suggested by focus group respondents as fundamental to avoiding real or perceived conflicts of interest. This was thought to be particularly important for people living in supported accommodation who might receive all their support from one provider, and people using the NDIS system. As one advocate said,

> Supported decision-making needs to be independent because in the NDIS system, no one is independent, not the support coordinator, the NDIA, nor the service providers. Service providers can be good, but that's lucky rather than by design, so there is a need for an independent person. (Advocate–generic)

Many respondents expressed a preference for a person having more than one supporter as a way of ensuring they were supported to consider multiple perspectives about decisions but also as a mechanism for safeguarding,

> …because when you're interpreting will and preferences, you have your own lens, and someone else can interpret things differently – to suggest that there's an objective truth is unhelpful – need to wrestle with different interpretations. (Service provider)

> Multiple supporters can produce transparency and checks and balances. (Advocate–generic)

As these quotes illustrate too, having multiple supporters may be particularly important for people with severe cognitive disabilities. For this group, supporters often rely on interpretation and experiment to understand their will and preferences. Most supported decision-making pilots have not included people with severe cognitive disabilities and have assumed that people have one primary supporter who coordinates the involvement of other supporters if there are any.

This is also the model of the La Trobe Framework, which emphases the significance of the primary supporter orchestrating the involvement of other supporters to ensure the person gains diverse perspectives, as well as ensuring others involved with the person, such as direct support workers, also practise good decision support. Similarly, focus group respondents pointed to the need for role clarity and collaboration when a person had more than one supporter.

> You have to be very clear with others (eg, care team) what your role as a supporter is, and how you're going to work. It can be very difficult. (Advocate–disability)
>
> People want all the different people who help them make decisions recognised…. have a key person who is adept at supporting a person to make decisions and understanding will and preference – and they oversee how others in the network operate with decision-making. (Professional)

Two models of group-based support for decision-making are described in the literature. The first, generally known as circles of support, is characterised by a group of people coming together on a voluntary basis to support a single person through relationships of trust.[210] Although various organisations have produced guides to establishing and maintaining circles of support, there is little evidence about effectiveness and one of the few evaluations of this type of model indicated it was most applicable for people with already strong family support.[211] The second model, a microboard, is similar to a circle of support but more formalised into as an entity with legal standing. This type of microboard model is more common in Canada than Australia, and similarly there is little evidence about its effectiveness (further Sections 5.3 and 8.3.1).

As discussed in Section 2.2.2, many people have little or no access to a single supporter, let alone multiple supporters, for decision-making. In some cases, having a supporter who is embedded in the service-system (rather than independent), is better than having no support at all, despite the conflict of interest.[212] In practice rather than ideal, best practice often involves inevitable trade-offs between conflicting priorities and adapting to circumstances.

5.4 Diverse supporter relationships

Supported decision-making happens within a vast array of unpaid and paid relationships, contexts and civil society arrangements. The diversity embedded into each of these means simple dichotomies of unpaid/paid supporters, formal/informal contexts or relationships, regulated/unregulated contexts, or private/public spaces are unhelpful to understanding the challenges that confront supporters and reformers in developing universal categories around practice issues. For example, irrespective of sector differences, supported decision-making may occur in private or public spaces, a person's home, in the community, a commercial business or a disability service. But a person's home may also be semi-public or a workspace if paid supporters are dropping in or their home is some form of supported accommodation service. Unpaid supporters may be family, friends, associates or volunteers. Regardless of the kin relationship, unpaid supporters may have very different kinds of relationships with the person in terms of length, closeness, intimacy or trust.

Unpaid supporters operate in very different civil society arrangements, some are free of any restraint or guidelines other than moral, but some are regulated as part of a formal program of volunteering or an appointment as a nominee or enduring power of attorney for specific types of decisions. Paid supporters may not hold any formal appointment as a decision supporter or be regulated as such. However, supporting decision-making may be a central part of their day-to-day work in a supported accommodation setting or in delivering professional services. They may be guided by directions in a person's care plan or by someone appointed as a guardian for the person they support. Their supported decision-making work may be regulated by a code of conduct or be integral to their job description and overseen by their employer who in turn is subject to various quality monitoring and regulatory oversight.

Alternatively, paid supporters may be formally appointed and recognised as a decision supporter, fulfilling their role as part of employment as, for example, a guardian of last resort in an office of the Public Advocate or Public Guardian. Or a paid supporter may have a role as dedicated decision supporter which may or may not be formally recognised, as for example part of the DSS funded pilot supported decision making scheme to enable access to the NDIS for potential participants.

Research shows that both paid and unpaid supporters provide supported decision-making for a myriad of different types of decisions, and those who give support on a daily basis shift almost momentarily between supported decision-making and 'personal and social wellbeing' substitute decision-making. They are continually exercising judgements about which approach to take, mediated by the decision, the context, the person and their own skills and values, or as suggested above, by following directions about particular 'risky' decisions. This view was reflected by focus group respondents who suggested a supported decision-making framework should be able to accommodate diverse types of support roles and relationships,

> ...it just depends on when the supporter is moving from just being a sounding board and helping someone think things through to where they're then maybe moving into a bit more of an advocacy type role where they're speaking on behalf of the person to get access to their personal information if they're interacting with an organisation. And then the next level is they're acting on behalf of the person to implement a decision. (Advocate–disability)

Just thinking about unpaid relationships and whether they should be recognised and treated differently from paid relationships in supported decision-making raises a host of issues. What differentiation needs to be made and why? How should unpaid relationships be framed and what do they encompass? Payment, for example, can change a close relationship from being altruistic to one where financial reward poses a conflict of interest. But it does not always do so, and lack of payment does not mean that relationships are without conflicting interests or risk. We believe a nuanced approach is needed, rather than simply banning those in paid relationships from being decision supporters or recognising all unpaid relationships. One such more nuanced possibility might simply be to require closer scrutiny of the circumstances before according formal recognition to paid decision supporters. Yet a workable trigger and form of scrutiny will be difficult to frame, beyond a heightened state of alertness to the risk.

The following categories may provide a useful lexicon for distinguishing between the diverse types of supporters in design of supported decision-making program.

- Informal unpaid civil society supporters (for example, family, friends, associates, volunteers) with no formal recognition as a decision supporter
- Unpaid civil society supporters with a formal appointment as a decision supporter for all or some decisions (for example, a friend appointed as a legally recognised supporter ('supportive attorney') in Victoria)
- Paid supporters who provide supported decision-making as part of their professional or support role and are monitored by their employer, subject to a code of conduct or professional registration requirements (for example, aged care workers or health care professionals)
- Paid supporters who are formally appointed and recognised as decision supporters (for example, a statutory guardian of last resort adopting a principled approach)
- Paid supporters who have a dedicated role in decision support but who may or may not be formally recognised (for example, an employed decision supporter in a funded pilot supported decision-making scheme).

5.5 Standing of supporters

Formal supported decision-making schemes generally accord legal standing to decision supporters to facilitate access to information, act on behalf of the person and conduct of transactions with other service systems or institutions.[213] This has been an element missing from pilot schemes which lacked the power to grant standing; this – compounded by the relative newness of formal supported decision-making – means there is little research about the impact on practice of formalising supporter standing. Neither is much known about the practice of substitute decision-makers such as NDIS nominees or guardians who have formal standing in respect of decisions. The ALRC guidance suggested that respect should be accorded to family and other close decision supporters chosen by the person, but this does not equate to legal standing, and is unlikely to satisfy the requirements many institutions insist on before sharing information or allowing someone to act on another's behalf.

Focus group respondents thought it was important in some instances to accord formal standing to unpaid supporters for the reasons outlined above but also, particularly to ensure the recognition of volunteer decision supporters without kin relationships to give them credibility,

> …service providers will be much more willing to involve that person if they're part of a program, they're not just some random stranger. (Advocate–generic)

One family member talked about the advantages she had experienced being formally recognised as a decision supporter in a healthcare context and suggested the benefits of such recognition in other aspects of a person's life.

> … if we’re talking about decision-making in houses or in people’s lives apart from health, then it’s that they might have a right to see key worker reports or the sort of internal documentation that families never see, or incident reports that involve the person concerned. … if you give people that title, then people kind of respect that title… I could imagine if I was given a title of Ned’s supported decision maker, whether I was Ned’s mother or his advocate or whatever role I had or his friend… then it would give me a kind of credibility to say to other people, ‘Well, look. This is how it’s best to support Ned in decision-making.’ I could then play a training role, if you like… it would give a credibility rather than oh, you know, yeah, she’s just arguing about it, she’s just Ned’s mum, you know? (Family–disability)

Whether or not formal recognition of unpaid supporters is necessary to enable best practice supported decision-making and the mechanisms for recognition, remain unclear. Unpaid/paid also may not be a useful category to distinguish between supporters. It may be more useful to think about differentiating between supporters who are formally recognised as decision supporters either by the legal system or a supported decision-making program, those who have no formal standing, and those who deliver supported decision-making as part of broader professional or support roles.

There is a significant gap in the evidence about this feature of supported decision-making, which should be addressed in future research about the practice of decision support.

5.6 Conclusion

A best practice approach involves building an evidence base on the effectiveness of different practices and programs in achieving the objectives of supported decision-making. This should be done in ethical ways that adhere to the principles of an agreed national framework. This evidence should be shared and used to develop detailed guidance about more effective practices within communities of practice, to allow replication, adaptation and further development of new practices.

Some common elements of best practice supported decision-making are already known to be applicable across diverse contexts and for diverse people. These include knowing the person well; understanding the person’s personal, social and service contexts; recognising the person is capable of participating in decision-making; being committed to creating opportunities for decision-making; taking time in supporting decisions; tailoring communication to the person’s needs; providing options to choose from; enabling risk; and maintaining active self-reflection.

Multiple supporters are preferable to one, and independence of supporters from service systems is also preferable in order to avoid conflicts of interest. However, it is acknowledged that in reality these and other elements of best practice are not always possible, and best practice frameworks should also be developed to reflect more challenging circumstances, such as the difficulty in recruiting and retaining multiple supporters, or the lack of time to carry out a more intensive support process.

In Chapter 2, we recommended as the third element of the Framework: '**Use of best practice and ethical supported decision-making** – Use of evidence-informed best practice frameworks in supported decision-making should be central to all supported decision-making programs and initiatives'.

Recommendation 5 Use of evidence-informed best practice frameworks in supported decision-making should be central to all supported decision-making programs and initiatives

5.1 The following categories be used to distinguish between supporters:

- Informal unpaid civil society supporters (for example, family, friends, associates, volunteers) with no formal recognition as a decision supporter
- Unpaid civil society supporters with a formal appointment as a decision supporter for all or some decisions (for example, a friend appointed as a legally recognised supporter ('supportive attorney') in Victoria)
- Paid supporters who provide supported decision-making as part of their professional or support role and are monitored by their employer, subject to a code of conduct or professional registration requirements (for example, aged care workers or health care professionals)
- Paid supporters who are formally appointed and recognised as decision supporters (for example, a statutory guardian of last resort adopting a principled approach)
- Paid supporters who have a dedicated role in decision support and who may or may not be formally recognised (for example, an employed decision supporter in a funded pilot supported decision making scheme).

5.2 A national repository of resources for best practice supported decision-making should be established and actively curated to assess the strength of evidence on which they are based and promote dissemination of evidence informed resources. This would serve as a resource for dynamic communities of practice in sharing knowledge and experiences of supported decision-making generally, or for specific groups or sectors.

5.3 Further research is needed on different forms of recognition or legal standing for paid and unpaid supporters, and their impact on the quality of supported decision-making.

5.4 Further research is needed in particular on how supported decision-making can work in the context of people with disabilities with severe cognitive impairments.

Chapter 6. Capacity building at individual, system, and institutional levels

This chapter focuses on the fourth element of the Framework; namely the crucial need for capacity building for supported decision-making in Australia. As previous chapters have demonstrated, supported decision-making education and training based on best practice is needed for those being supported as well as the wide range of potential supporters across many sectors. This is necessary if holistic change is to be at all possible in Australia.

6.1 Developing awareness and skills among supporters, service systems and community

Building the capacity of decision supporters to give effective support through training and mentoring has been a primary strategy employed by the pilot supported decision-making programs in Australia.[214] It is widely recognised that unpaid supporters in particular need information and training[215] and there is a growing body of evidence that demonstrates the impact of training on different types of decision supporters including: family members; substitute decision makers in financial administration schemes and healthcare contexts;[216] and professionals working in health, disability and aged care services.[217] In a recent essay, Donnelly extends the focus of capacity building from skills training to include the service provider's attitude, approach and abilities about supported decision-making. She advocates that all professionals across the spectrum of health to financial sectors should be prepared and expected to give support for decision-making.[218] In part this is because for the most socially isolated, this approach presents one of the few opportunities to receive supported decision-making for decisions that impact their lives.

Similar to Donnelly, respondents in our study took a broad approach to capacity building for supported decision-making. They recognised the broad range of professionals likely to be in touch with people with cognitive disabilities who would benefit from capacity building, including, lawyers, GPs, nurses, allied health workers. One respondent talked about the importance of building the capacity of medical staff to include issues of decision-making along with other key information when a person is diagnosed with dementia,

> On diagnoses, you are advised about: 1) your money, 2) health. Should be: 1) your family should be told about supported decision-making; 2) you should be told about consent around what happens with your body, and 3) your money. Without capacity building, wives and partners have no way to support the person. (Advocate aged care)

They saw that building knowledge about supported decision-making needed to occur across multiple systems and at multiple levels: for unpaid and paid supporters, individuals with cognitive disabilities themselves, professionals working in different systems. This would be needed to increase awareness and change institutional cultures of all types of health and community services, so that supported decision-making becomes the expected and default practice.

They saw capacity building as a key element of a supported decision-making framework and as an underpinning strategy for its implementation. Indeed, there was significant optimism that a broad range of strategies, some with targeted audiences and others more generic, could: increase the skills of all potential supporters; assist people with disabilities to know their rights to support; maximise effectiveness of support; raise community expectations about involvement of people with disabilities in decision-making and contribute to cultural change.

> Need a policy structure to enable community capacity building. (Family-disability)

> Need community to be more aware of good supported decision-making so it can lead expectations. (Advocate–disability)

One rationale for the emphasis on capacity building was the limited knowledge and divergent understandings of supported decision-making across sectors and the educative demands experienced and revealed by some pilot supported decision-making programs. As one respondent involved in a program said,

> we spend a lot of time educating service providers and others around what the rights are of the person, what decision support is, and what the requirements and how they might differ to what the service provider is requesting. …we often, we have a number of requests along those lines …just recently we had someone from NDIS refusing to do a review of a reviewable decision because they don't believe the person has the capacity to provide that instruction…. I think a lot of education needs to take place… with service providers and the NDIS, and others. (Advocate–disability)

Respondents saw the potential of capacity building to shift long-held misconceptions of some paid and unpaid supporters about people's capacity to participate in decision-making and equip them with strategies more aligned with supported decision-making principles.

> Families can be transformed by capacity building. (Family–disability)

> Supporters need to be trained and understand influence and subtle coercion, and how to be objective and neutral. (Advocate-generic)

Larger disability or aged care providers were seen as important targets who, by adopting policies about supported decision-making and training their own staff, were likely to influence the expectations and skills of direct support staff.

For supporters whose approach was already aligned with rights, capacity building would assist in giving them more insight into what they were doing and equip them with a language of support that could be shared with others.

> Parents and others want to know what it is, and formally, how they might do it – even if they've always done it intuitively. (Professional)

Building knowledge about supported decision-making across systems was also seen as an important part of safeguarding that would help ensure there were multiple eyes watching out for a person – people who could identify and raise concerns if necessary.

> Need to have 'a general community awareness and understanding of what supported decision-making should look like' in order to pick it up where the wrong thing is being done' and to rectify it through education. (Service provider)

As discussed in Section 1.4 and recognised in the Framework, the dignity of risk for people with cognitive disabilities is acknowledged and supported. As part of this, risk enablement education and training should be given to supporters, institutions and organisations to reduce the overly protective approach to minimising all risk that exists in some areas in Australia.

6.2 Building capacity of people with cognitive disabilities

Self-advocacy in the field of intellectual disability has since its inception in the early 1980s, been a vehicle for enabling people to understand and speak out about their rights. It remains at the core of the various projects underway in Australia that aim to build the capacity of people with cognitive disabilities to understand their right to supported decision-making, use support effectively and lead the development of supported decision-making in the services they use.[219] Some of these projects are funded as NDIS Information Linkage and Capacity Building projects or from other short-term sources of funding. Most have not been evaluated or are still works in progress. Many of these projects are taking innovative approaches. However, this is an area where there has been little research, and where evaluation of such initiatives will be important in developing evidence on which models are effective.

With the right developmental opportunities, experiences and support it is likely that some people with intellectual disability will increase their capacity for decision making. There is a strong body of research on self-determination from the disciplines of psychology and education which aligns quite closely with ideas of building the capacity of people with cognitive disabilities for supported decision-making. This work is primarily focussed on children and young people with intellectual disabilities and aims to understand the factors that influence self-determination and develop strategies to better equip people with associated skills.[220] We did not explore this in any depth in the literature, as it is a field of research in its own right.

However, focus group respondents emphasised the need to build decision-making capacity more specifically, rather than simply inculcate a broad understanding of rights. Specifically, for people with lifelong disabilities, many respondents considered it important to build their decision-making skills and experiences from an early age. For those who were now adults, but whose skills and experience of decision-making had been neglected in their younger years, significant upskilling was needed.

> We need education in decision-making, because if people haven't made decisions in the past, they won't understand options and risks. (Advocate–generic)

For those still young this should start early both at home and at school,

> Supported decision-making needs to start early for people with intellectual disability – when they start school or earlier, so you build supported decision-making into their educational environment and develop help-seeking behaviours. (Advocate-generic)

The NDIS 'Early Intervention' funding represents one opportunity to achieve this. It gives access to NDIS support funds at an earlier age where this leads to reduced support needs in the future.

More broadly, there is some evidence that changes to the nature of supported decision-making and expectations of supporters positively impacts on the confidence and decision-making skills of people with intellectual disabilities.[221]

6.3 Strategies for capacity building

Building capacity for supported decision-making entails developing and implementing strategies to change knowledge, attitudes and skills across multiple societal levels. Most commonly these revolve around education, training and production of resources tailored to specific groups. These were the types of strategies focus group respondents had been involved with, as one service provider said,

> Couldn't do more than bring in as supportive a system as possible – tried to promote and support good supported decision-making, i.e., training families, workers, support coordinators, Local Area Coordinators. (Service provider)

Other than training for decision supporters and work around building capacity for self-determination in students with intellectual disabilities, there is little evidence about effective capacity building strategies. Several comments from focus group respondents suggest that proactive approaches are needed rather than relying on 'self-serve' passive resources.

> I think there's some terrific websites that promote supported decision-making for mental health. I don't see it having much traction. It's pretty hard to judge…but I often ask people - have you seen that website? It talks about supported decision-making. Nah. Or, nah, it didn't make sense to me. So, I understand there's some really good ideas behind all that, but it's how do you get to the person in a sufficient format that they can start to at least grasp what's being offered here. (Advocate–mental health)

Capacity building is part of quality assurance, and thus many of the strategies discussed in the next chapter around oversight are also likely to build supporter capacity. These include for example: requirements to include supported decision-making in curricula of professionals; staff competencies or accreditation in supported decision through micro credentials and requiring appointees to formal supported decision roles to complete training or report annually on their practice.

Focus group respondents also thought checklists and reflective practice derived from best practice models were useful tools for capacity building as discussed in Section 5.2.

> …a checklist ensuring that each person that might give advice or is part of that, is almost like a declaration of upholding those rights of an individual within those situations that they've been taken into consideration, within a framework and very transparent to say, 'I advised this person this,' and took into account the different human rights, like a checklist to ensure that things aren't skipped and to give transparency over the parties involved and even maybe examples. (Family–disability)

There is enormous potential for innovative capacity building strategies that aim to change service cultures and supporters' attitudes around supported decision-making, particularly those that include people with cognitive disabilities or their families in leadership, design and delivery. Increasing public awareness about supported decision-making principles and tools,[222] can also be a component in capacity building, potentially as part of wider initiatives to promote the rights of people with disability in line with the CRPD.[223] As a signatory to the CRPD, under article 8, the Australian Government is committed to taking 'immediate, effective and appropriate measures' to raise public awareness and foster respect for disability rights. This includes specific measures, such as: public awareness campaigns; embedding respect for rights at all levels of the education system from an early age; encouraging media coverage of disability-related issues consistent with the CRPD, and more targeted training programs.

Inter-sectoral collaboration across different tiers of government, business and civil society organisations, educational institutions and the broader community, is a crucial facilitator of effective campaigns to raise public awareness on disability rights issues, including supported decision-making.[224] As discussed elsewhere in this Report, important roles are assigned to Offices of Public Advocates and Public Guardians in different states, which are charged with systemic advocacy and public education responsibilities (see also Section 4.3 and Recommendation 7.1); and disability advocacy organisations which, with appropriate resourcing, could play a lead role in raising public awareness of supported decision-making (see also Section 9.1). Funding for public awareness and capacity building campaigns and programs can be sourced through the NDIS Information Linkages and Capacity Building scheme; however, the short-term project-based nature of such funding may not be sufficient to sustain advocacy efforts over time.

The media can also raise awareness of supported decision-making. In the USA, media coverage of Britney Spears' conservatorship legal proceedings and the #FreeBritney movement has increased public awareness of conservatorships and prompted nation-wide calls for reform.[225] However, such media coverage can also reinforce a binary understanding of supported and substitute decision-making, which as we argue in Chapter 1 can be problematic. Effective disability rights campaigns often focus on positive media coverage,[226] suggesting the advantages of more positive media coverage on the benefits of supported decision-making.

Mittler highlights social media platforms as powerful tools to raise public awareness of the CRPD in general, and supported decision-making in particular.[227] As with traditional media, there is a need for positive messaging on the principles and benefits of supported decision-making.

The Office of the United Nations High Commissioner for Human Rights highlights the responsibility of public inquiries for promoting public education and raising awareness.[228] Through its public dissemination efforts, the Disability Royal Commission can promote understanding of a principled approach to supported decision-making, and the necessary changes in the community, government, market and diverse service systems, as articulated throughout this Report.

However, assessing effectiveness of this type of broader social change rather than changed individual skills is challenging and suggests the pressing need for longer rather than short-term demonstration programs which allow sufficient time for strategies to be refined and change identified.

6.4 Conclusion

Capacity building across different sectors for supporters is essential to enable the Framework to succeed. As mentioned in Chapter 5, embedding knowledge of supported decision-making and best practice across sectors and professions is one way to account for the disadvantage experienced by those who might not otherwise have access to supported decision-making due to social isolation.

It is also necessary to ensure people with cognitive disabilities have access to capacity building to develop their experience of decision-making and skills in using available support. This is particularly important across the life course for people with intellectual disabilities whose continuing developmental capacity for decision-making is contingent on high expectations of others and opportunities available in their daily lives.

In Chapter 2, we recommended as the fourth element of the Framework: '**Capacity building at individual, system and institutional levels** – Capacity building at the individual, system and institutional level must be a key strategy for implementing all aspects of a Framework for supported decision-making.'

Recommendation 6 Capacity building at the individual, system and institutional level should be a key strategy for implementing all aspects of the Framework.

6.1 A key focus in the design of new supported decision-making programs and initiatives should be capacity building of paid and unpaid supporters.

6.2 There should be a focus on capacity building of people with cognitive disabilities that enables development of their skills in decision-making and / or optimal use of available support for decision-making. This is particularly important across the entire life course for people with intellectual disabilities.

6.3 Particular attention should be given to capacity building initiatives that account for the needs of diverse people, by disability type and severity, and for people from diverse cultural backgrounds and First Nations peoples.

6.4 Awareness of supported decision-making and skills in best practices should be built into the NDIS workforce competence framework and core competencies of all professionals involved in health, aged care, legal, financial, human service and criminal justice systems.

6.5 A proactive approach is needed to disseminate capacity building resources, especially to informal supporters. This should include proactive circulation of information about resources through diverse media and networks, and incentives for supporters to actively engage in capacity building programs.

6.6 To move away from a culture of protection to one that enables people to take on and experience risks, all supporters, organisations and institutions involved with people with cognitive disabilities should have access to education on risk enablement and the positive aspects of risk taking to avoid an overly protective approach to all types of risk.

6.7 To increase awareness, understanding and respect for disability rights, and decision-making rights in particular, there is a need for public awareness campaigns and embedding content on disability rights in the education system.

Chapter 7. Safeguarding, quality assurance and oversight

The success of supported decision-making is heavily dependent on the quality of support available to a person, and for people with more severe cognitive disability, often relies on interpretation of will and preferences rather than direct verbal expression. Much day-to-day supported decision-making happens in private spaces not open to public scrutiny and in relationships of unequal power, be these paid or unpaid. These features create possibilities for manipulation, undue influence and abuse by supporters and mean, as the CRPD and ALRC recognised, that safeguards, quality assurance and oversight must be integral elements of a framework.[229] As noted by Kohn:

> One of the primary worries, even for those advocating supported decision-making, is the potential for coercion or other inappropriate influence by a representative or supporter. Exploitation and abuse certainly occur in guardianship contexts (although it is unclear how frequently), and supported decision-making arrangements create new opportunities for abuse. Indeed, when we turn to more informal arrangements such as supported decision-making, which may occur in private and with less accountability, the potential for financial or other abuse likely increases.[230]

Kohn and Blumenthal[231] and others argue that undue influence is likely to be a greater issue in supported decision-making arrangements than formal substitute decision-making due to the 'untransparent and potentially unfair distribution of responsibility' and the absence of the checks and balances that may be normally present when substitute decisions are made.[232] Some of these concerns are now well described by research on practice of both paid and unpaid decision supporters.[233] Concerns also extend beyond the informal to formal supported decision-making arrangements where for instance private, self-executed supported decision-making agreements, often implemented in family settings, may mean that such relationships are insulated from scrutiny and 'magnify the risks of their deliberate abuse'.[234]

Focus group respondents saw that quality assurance and oversight of supported decision-making arrangements and practice should be an essential part of a framework. Nevertheless, they were sceptical about the possibilities of doing this effectively, both in terms of social acceptability and what they saw as the failure to invest sufficient resources in monitoring service standards or worker codes of conduct. They had little confidence that, without significant investment of resources in design and implementation, regulation was likely to have other than unintended consequences and easily become burdensome and ineffective.

> …regulatory systems struggle, I think, to deal with these issues very well, so that difference between encouraging good practice as opposed to trying to regulate…No question, you need to have that power to get rid of the really bad ones… but the real issue is probably around generally our capacity to really track and look at quality improvement is very difficult to achieve in modern bureaucratic systems. (Advocate-mental health)

> Just registration of provider with NDIS and quality audits are not enough…they have 'beautiful' policies. (Advocate–disability)

> Aged Care Standards already endorse supported decision-making principles, but there is no funding investment. (Advocate–aged care)

This chapter identifies the various ways in which quality assurance and oversight may occur across the diverse contexts in which supported decision-making is practised.

7.1 Quality and oversight of informal unpaid support

Informal supported decision-making, like elder abuse and child neglect often occurs in a private context which makes monitoring its quality, particularly challenging. Many focus group respondents felt strongly that oversight of supported decision-making should differentiate between unpaid informal decision supporters and those who play that role in a paid capacity or have some type of formal recognition.

> Families shouldn't be treated the same as workers. (Advocate–disability)

They raised questions about the reasonableness of scrutinising informal supporters and its impact on their willingness to undertake the often onerous, unpaid emotional labour of supporting decision-making.

> Hard to monitor informal supporters or make people accountable in private relationships. There needs to be a space for informal decision makers who are doing the right thing to continue on without unnecessary intrusion. (Service provider)
>
> The average family wouldn't want an 'inspector of decisions' – very hard to implement. (Advocate–disability)
>
> …anything that creates a burden or obstacle to maintaining informal supports would be really problematic – a tricky balance. (Advocate–generic)

Rather than monitoring unpaid informal supporters, focus group respondents saw the primary means of having oversight of supported decision-making, as stemming from capacity building. As already noted, they advocated for greater community awareness and increasing the social connections of people with cognitive disabilities – having 'multiple eyes watching out' for a person who are aware of good practice and willing to raise concerns when they think things are not right. Over time and with sustained capacity building strategies, the ability of the community in general, of service providers and other professionals to be alert to signs of malfunctioning supported decision-making is likely to improve. Progress, however, is likely to be slow and hampered by the pressures that result from understaffing and underfunding, particularly in the aged care and disability support sectors.

Not all unpaid supporters operate completely in the informal sphere: some are recognised formally, albeit in respect of specific types of decisions. Such recognised roles include nominees for NDIS or Centrelink related decisions. It is also likely that, as supported decision-making programs expand, more unpaid supporters will be accorded various types of formal standing, as in the case of supportive attorneys, supportive guardians and medical support persons in Victoria.[235] Interestingly, in contrast to the majority view of focus group respondents, several parents of people with disabilities were less concerned about oversight, such as annual reporting or audits, once they crossed from an informal to a semi-formal role such as being appointed as a person's primary decision supporter as part of a supported decision-making program. Indeed, they were used to requirements such as annual reporting, which is currently required for formal roles such as a guardian or administrator. As one respondent said,

> when it comes to a more formal status, perhaps a supported attorney role or a nominee correspondent, then in entering that legal agreement one would have to, as is currently the case, agree to certain behaviours and standards that you would uphold in doing so. And I suppose if those standards were breached, then someone, say a support worker, another citizen, another family member, could point out ways that it has been. And I suppose there would be almost a reactionary policing, for want of a better word, of a breach of that trusted role. (Family–disability)

The scope to offer unpaid supporters incentives to improve the quality of supported decision-making will also increase as more become recognised in some way. Thus, it might be possible, for example, to target education campaigns to all supporters of particular populations – such as NDIS participants, people in receipt of carer payment or allowance, as well as those who hold some formal standing such as nominees. Incentives offered might include measures such as a designated supplement to recipients of care-related social security payments to engage in training, or a payment to nominees who lodge an annual 'diary' of their activity.

Where abuse by a supporter is suspected, recourse can be made to existing processes that enable concerned persons to make a report to the offices of the Public Guardian or Public Advocates or other relevant bodies across Australia.[236]

7.2 Quality and oversight embedded in legislation for appointed supporters

Most safeguards identified in the literature focus on imposing responsibilities, control and oversight on supporters,[237] recognising the often unequal relationships that exist between them and the person they support. However, as noted by Bartlett: 'how it is to be done is at best unclear, without the development of a system that is both unwieldy and intrusive'.[238] In some jurisdictions, including US states (including Delaware, Alaska, the District of Columbia and Rhode Island) and Ireland, restrictions have been placed on those who can act as a legally recognised supporter.[239] This includes employers/employees, anyone against whom the decision-maker has a restraining order, and individuals directly providing paid support services to the decision-maker.[240] Table 5 summarises some of the common local options from NSW, Queensland and Victoria.

Table 5. Existing monitoring and oversight mechanisms for legally recognised supporters (Vic) and substitute decision-makers (NSW, Qld)

Legally recognised support persons in Victoria (i.e., supportive guardian, supportive administrator, supportive attorney, medical support person)	Legally recognised substitute decision-makers in Vic, NSW, Qld
Advice or directions can be sought from the tribunal by a supporter If self-appointed, the person who appointed the supporter can revoke that appointment if they have decision-making capacity to do so. Offence committed where supportive guardian or supportive administrator uses their position to obtain financial advance or cause loss to the supported person or another person. Offence committed to purport to act as a medical support person.	Periodic review by tribunal of appointed guardians / administrators. Interested person (including Public Advocate) or the person themselves can approach tribunal (or the tribunal on its own initiative) for review / revocation of appointment of a substitute decision-maker. Duty to keep records – administrators only. Public Advocates/Public Guardians have designated roles for some types of decisions (eg, Public Advocate role in Vic re: refusal of health care by substitute decision-maker; role of Public Guardian in Qld when substitute decision-maker does not apply the health care principle; mediation of disputes and referral of matters to tribunal). Advice or directions can be sought from the tribunal. Person can change or revoke any appointment if they have decision-making capacity to do so.Offences applicable to substitute decision-makers (eg, making health care decision when it is known they had no right to do so; for substitute decision-makers who use their roles dishonestly).

Strategies have also included explicit legislative duties on supporters to, for example, refrain from undue influence.[241] In a similar vein, one focus group respondent in our fieldwork suggested the value of formalising informal supporters' roles, through mechanisms such as supported decision-making agreements so that expectations could be made clear,

> I think that a formal tool can help contain a supporter, an overzealous supporter because you say what the supporter could do because without that specification, there can be some vagueness around what a supporter's allowed to do. (Advocate–disability)

Other legislative provisions have imposed fiduciary duties on supporters[242] which may also involve submission of periodic reports to a government oversight body (as is the case in Ireland).[243] Serving a similar function are both periodic and on-request court or tribunal reviews of support arrangements. Such review arrangements were highlighted in Argentinian reforms and include the supported person's right to be heard on their own, or with support.[244] An interesting innovation that places the issue of safeguards in the hands of the person with a disability exists in Peru, where people can nominate their own safeguards, including reporting, audits, periodic supervision, interview and information requests.[245]

In Victoria where supported decision-making arrangements are formally recognised, the VCAT has been given powers for overseeing supporters similar to those they hold for substitute decision makers, including annual review and reporting requirements. These safeguards have the advantage of being routine, not reliant on a member of the public for initiation. Other types of safeguards with this more proactive character might include expanding the watching brief of people serving as community visitors or disability advocates to also include being alert to indications that a supported decision-making arrangement has become problematic.

Throughout Australia, all privately made decision-making arrangements (enduring powers of attorney over finances, health, or personal guardianship) are reviewable and can be terminated by state and territory guardianship tribunals.[246] Offices of the Public Guardian or Public Advocate in most jurisdictions also have the ability to do likewise on their own initiative or assist a member of the public by taking carriage of a concern that is reported to them. While largely cost-free and able to be initiated by any member of the public, this type of safeguard relies on someone recognising an issue of concern and setting a review in motion.[247] The effectiveness of this type of safeguard depends on having sufficient community awareness and high professional practice standards relating to the identification and referral of suspected abuse by supporters. Public and professional education initiatives would therefore be needed as an essential adjunct.

7.3 Service standards, accreditation and professional competencies

Given the diverse contexts and the diverse range of paid supporters involved in supported decision-making, various public institutions already have an existing or potential presence in quality assurance and practice oversight. This includes for example, through standards and accreditation of services and workers in the NDIS and aged care sectors, and professional registration and codes of conduct for allied health, medical, legal and financial professionals.

For example, standard 1 of the Aged Care Quality Standards framework recognises that 'consumers who need support to make decisions are expected to be provided with access to the support they need to make, communicate and take part in decisions that affect their lives'.[248]

Focus group respondents saw the existence of standards alone as insufficient quality assurance mechanisms. In their view standards needed to incorporate indicators of good practice that could be proactively monitored or reported against and were tailored to the role and context of a supporter. They pointed for example to,

> …need to develop some good indicators for supported decision-making – some could be anecdotal – simple as 'what's the evidence they got choice of clothing?' Where has a person had 'opportunities to choose what food they eat, when they go to bed, when they don't go to bed, and stuff like that?' (Family–disability)

> Need mandatory KPIs for supported decision-making and record them so they can be audited and a worker is then rewarded for taking the time to practise supported decision-making. (Advocate–aged care)

> And the quality standards should have supported decision-making embedded and how you report against it – consumer experience reports need to ask about supported decision-making. (Advocate–aged care)

Various ideas for quality assurance indictors that could be embedded into standards were suggested by focus groups respondents. These involved recording supported decision-making processes, using checklists, videoing interactions, or comparing supported decisions to earlier documented preferences of a person. Some of the suggestions came from their own practice as part of pilot programs.

> We record the process, are clear about the steps. (Advocacy–disability)

> Paid supporters can record the process as part of their supervision… Could do written description, or a conversation (or supervision) of how you've gone through the [practice] framework, – gives a good step by step guide – don't have to do it for every decision. (Family–disability)

One respondent suggested using information from internal quality control and feedback groups with residents as evidence for auditors about processes.

> Internally aged care homes are required to run their own consumer engagement and focus groups. Feedback from those is provided to assessors – so can demonstrate the residents have been consulted on a range of things from food to activities to quality of care. (Advocate–aged care)

This type of proactive monitoring of standards was acknowledged by respondents as time consuming and labour intensive, which raised questions about the viability of implementing them. Even more resource intensive were the examples of 'ideal type' monitoring of supported decision-making given by several respondents from their own experience.

> For the group home which she set up, they put in place a psychologist once a month, who didn't meet with parents or staff, who just met with residents so that they could have an independent voice. (Professional)

> …one of my son's communication partners will sometimes do a phone video of their conversations and then we can look at it. (Family–disability)

Other approaches to quality assurance involve embedding supported decision-making skills and competences into workforce competencies or professional accreditation or educational curricula. Focus group respondents said for example that,

> … [we] could have a code of conduct as a starting point. Problem is how to enforce it? Registration and then de-registration if breach? (Advocate–generic)

Competence in supported decision-making is already built into the NDIS Quality and Standards Commission workforce competencies, and code of conduct.[249] But similar to standards, these need indicators and active monitoring to be effective. Even iconic and supposedly universally adhered to ethical or professional codes can have negligible impact unless there is a tangible connection to professional life such as accreditation of a unit or professional registration. Bearing this in mind, a productive longer-term approach might be to have legal, health and welfare professionals to complete supported decision-making on-line protocols or in-person training sessions, as a mandatory part of professional accreditation. Pipeline effects in terms of members of the medical, legal, social work, nursing, allied health and disability services workforces might also be boosted through inclusion of modules on supported decision-making as part of the curriculum. Incentives in the form of special awards or accreditation standards might be introduced to give status and signal expertise to the public.

The traditional command and control regulatory models – involving setting standards, monitoring compliance through inspections, complaints or requiring regular accreditation – are not equally effective in all settings. There is a strong body of evidence to suggest that frontline medical and associated health workforces in care settings may respond better to ‘professional review or second opinions’, and that administrative settings similarly have their own rhythms and processes that optimal regulation needs to accommodate.[250]

7.4 Stringent measures for high-risk decisions

As suggested in Chapter 1, issues of risk and lasting harm to the person pose limits to supported decision-making. Where supported decision-making ends and substitute decision-making that takes account of personal and social wellbeing as well as will and preferences begins, will always be unclear. Use of existing tribunal processes for safeguarding appointment of guardians would run contrary to supported decision-making principles and at most should be the very last resort. Instead, the focus should be on inculcating the highest standards of reflective good professional practice, including measures such as documentation, justification of reasons, peer discussion and routine revisiting of such decisions.

Focus group respondents envisaged circumstances where a supported decision may have lasting or serious consequences which may not necessarily entail such harm or competing rights. For these types of decisions some rather surprisingly suggested measures that might be expected to deter informal supporters from taking on the role, such as formal documentation of processes and scrutiny by an independent oversight body should occur.

> If there is only one supporter for a significant decision, you may need 'more strident safeguarding, or you'd want multiple perspectives in situations that involve serious risk …to the person or others. That way you could target resources at the more significant decisions – maybe the sale of property – 'some independence around decision-making that was happening there would be feasible and reasonable to expect'.… there could be a policy that would require something more significant than just documenting a regular process. (Service provider)

> Maybe not a guardian in its current form but someone who looks at the decision proposed to be made and I guess tests the veracity of that decision in terms of what the person might choose for themselves… (Advocate–generic)

> When making a 'best interpretation' of a person's will and preferences and the consequences are serious – eg, life-altering surgery – need 'some means to intervene beforehand' and 'have people record the reasoning for their interpretation of will and preferences…' (Family–disability)

One possible independent agency to consider as part of the design of these measures may be the watchdog role of existing offices of the Public Advocate or Public Guardian, in serving as the 'eyes and ears' for such concerns. Utilising such existing infrastructure and agencies with experience of decision oversight may be preferable to establishing new bodies dedicated to oversight of supported decision-making, as has been the case in Ireland. This was the view of focus group respondents who, although they saw the necessity for one or more bodies to take responsibility for developing capacity and oversight of supported decision-making, were reluctant to establish new ones.

> 'I'm not imagining some new agency that gets set up to check on supporters of decision-makers; to administer it would be heavy-handed, and not a good use of resources.' (Advocate–generic)

> Probably the OPA because the community visitor program is close to it. Parents do have confidence in the OPA. (Family–disability)

If existing infrastructure is used it will need additional funding to account for greater roles including education and oversight of supporter relationships.

7.5 Conclusion

This chapter proposes that, rather than a uniform approach, particular styles of quality assurance and monitoring might best meet the needs of the different settings in which supported decision-making occurs. For example:

- Administrative/bureaucratic logics for construction of monitoring would appear to be best suited to oversight of fidelity to purpose for the high-volume administration nominee provisions and appointment of formal supported decision makers;
- Professional review/quality assurance logics operating through offices of the Chief medical officer/Chief psychiatrist, overseen by general or sector specific health complaints bodies (as in Victoria) and professional education, postgraduate and professional development accreditation training requirements may continue to be favoured in health/medically dominated settings, such as acute and community mental health; and in general health settings (where advance directives and other such powers arise); and
- Worker or professional codes of conduct, practice guidelines, in service supervision and oversight by quality regulators such as the NDIS Quality and Safeguard Commission and the Aged Care Quality and Safety Commission may be best suited to non-healthcare professionals and supporters in the disability and aged care sector.
- External tribunal merits review logics might continue to be favoured for monitoring fidelity to purpose of exercise of enduring powers of attorney/financial administration (i.e., by the already familiar and validated frameworks and institutions developed for Australia's reformed adult guardianship regimes).

Given the experience of regulatory failure of quality assurance and complaints oversight in residential aged care, as documented by the Aged Care Royal Commission and the Carnell Review,[251] it is premature to speculate on the choice of logic to inform design of monitoring of residential aged care and disability services.

In addition to statutory and formalised forms of monitoring, a degree of 'soft monitoring' exists in the interface of informal supporters with formal services such as healthcare or social services. These service encounters give opportunities for transmission of knowledge about supported decision-making, and oversight on the practices of supporters.

In Chapter 2, we recommended as the fifth element of the Framework: '**Safeguarding, quality assurance and oversight** – Approaches to safeguarding, quality assurance and oversight should be adopted using strategies that best meet the needs of the different settings in which supported decision-making occurs and are proportionate to risk'.

Recommendation 7 Approaches to safeguarding, quality assurance and oversight should use strategies that best meet the needs of the different contexts in which supported decision-making occurs and are proportionate to risk.

7.1 Existing disability rights advocacy organisations and decision support infrastructure – such as offices of Public Advocates, Public Guardians and tribunals – should be appropriately funded and used to deliver education, guidance and oversight of supported decision-making practice.

7.2 Different approaches to safeguarding and monitoring are required for the various different types of supporters.

7.3 Education, training and financial incentives – rather than external regulatory monitoring, ‘codes of conduct’ or punitive measures – should be applied to improve the quality of supported decision-making by unpaid supporters.

7.4 For formal supporters a range of measures are needed such as service and professional codes of conduct, standards or accreditation about supported decision-making.

Chapter 8. Forward planning, funding and building social connections

This chapter discusses the final three elements of a Framework for supported decision-making: enabling forward planning; adequate funding; and formal strategies for building social connections. The first of these three elements represents the potential to change expectations about the way nominated supporters will carry out their role in making future decisions with a person. The second, adequate funding, is an element necessary to bring about change and enable supported decision-making to become embedded in services. The third, formal strategies to build social connections, is an element that in the longer term will combat social isolation of people with cognitive disabilities, reducing inequities and reliance on paid decision supporters.

8.1 Enabling forward planning

Forward planning enables people to make arrangements for a future time when they might need additional decision support, for reasons such as declining cognitive capacity (as with dementia) or its sudden loss (due to brain injury or stroke). People with cognitive disabilities who want to, should be enabled to plan ahead.

While forward planning generally encompasses thinking about the future and discussions with loved ones (and possibly professionals), there are also legal instruments which can be used to record decisions made or wishes held about what a person wants for themselves in the future. These include appointments of substitute decision-makers for health, lifestyle or financial decisions (discussed in Chapter 4). These are formal legally recognised ways of documenting wishes for the future. As these legal instruments currently require a person to have a threshold of decision-making capacity, most people with existing cognitive disabilities are excluded from executing and using them. For example, although provisions in Victoria for making advance care directives for end-of-life care include the possibility of appointing a support person to assist in decision-making, a person must still reach a threshold of capacity with support in order to make a directive.[252] Existing forward planning mechanisms are also often associated with substitute decision-making (see Section 4.3).

The process of forward planning should include the option of nominating a future decision supporter as well as expressing a person's wishes generally or about specific likely events such as end-of-life care. Reforming and expanding legal options to include the ability to appoint decision supporters also has potential for realisation of a principled approach to supported decision-making, because of the large number of citizens who can be supported this way. However, forward planning also raises challenges. This is partly due to current legislation mostly granting substitute decision-making powers, but also because will and preferences can change over time in a way that a person cannot always predict and plan for.

Focus group respondents from across the aged care, disability and mental health sectors saw the value of forward planning mechanisms as an element of supported decision-making. Most commonly mentioned were legal advance care directives that expressed a person's values, specific instructions or nominated a future substitute decision maker about end-of-life care or medical treatment. Respondents suggested these were increasingly becoming a requirement of aged care services, increasing autonomy for individuals but also reducing risk for service providers.

> Need to get end of life things done long before dementia comes in… have to choose the right people. (Advocate–aged care)

Supported decision-making through forward planning can also be useful for people with intellectual disability. Several respondents raised the potential value of forward planning for future transition of a primary decision supporter when a person's primary carer dies. As one family member said, this could avoid unnecessary formal processes.

> If you have recognised/appointed role of a supported decision-maker then when parent dies, it is also recognised that someone needs to step into the role – maybe have a list of default decision-makers – like the 'person responsible' hierarchy – don't want to have to go to VCAT every time – only if someone challenges the hierarchy. (Family–disability)

Advance appointment of a future decision supporter for a person with intellectual disability might help assuage the anxiety of parents about what happens when they die. It can also help avoid parents making rigid plans about the future (for instance about accommodation and support) for their middle-aged son or daughter, that don't take account of the person's continued development or their preferences. Advance appointment of future decision supporters would offer further flexibility and opportunity for involvement of the person themselves at the time decisions have to be made rather than others anticipating the decision ahead of time.[253]

Another potential benefit of using legal instruments for forward planning is the opportunity for the person appointed as a future supporter to get to know the person they will support better. This can improve the quality of decision support in the future when the plan is activated (see Chapter 5).

However, respondents also saw problems with forward planning legal instruments. For older people, honouring advance care directives was seen as challenging given the changes that might occur over time to a person's preferences. This issue was summed up in one focus group discussion,

> So, if you're someone whose made an Advance Care Directive prior to diagnosis for dementia, there's one line of thinking that suggests that should be honoured regardless of any changes that you might experience if you have cognitive impairment or dementia…Then there's another whole line of debate that argues, 'Well no, dementia is a transformational experience and that any changes that occur, in that experience, need to be respected, and any change in wishes accordingly, including in relation to health needs, also need to be respected.' …There is a middle line here, and it's actually what many people, supporting people with dementia, do anyway which is balance. Knowledge of previous wishes, whether documented or otherwise, or just verbalised, and current wishes or preferences if they're expressed and even if they've changed. (Advocate–aged care)

As discussed in Chapter 4, some existing legal instruments which provide for substitute decision-making such as enduring powers of attorney, can be adapted to overcome some of these problems by embedding supported decision-making principles within their operation. (See recommendations in Chapter 4).

A forward planning appointment of a supporter is one way of furthering supported decision-making principles. Victoria is the only Australian jurisdiction that provides a legal option to make this type of formal appointment in the form of a supportive guardian or supportive financial administrator.[254] However, this model has two significant design flaws. First, the requirement to demonstrate decision-making capacity before a person can appoint a future supporter, and second, the termination of an existing arrangement if capacity is deemed lost.

First, the threshold, of having 'decision-making capacity in relation to making the appointment', sets the bar too high. Although capacity to understand risk of imminent, serious and lasting harm is an important consideration in a principled approach to supported decision-making (see Section 1.4), the Victorian insistence on demonstrated capacity arguably does not fully align with the principles of supported decision-making, and warrants reconsideration.

The second and arguably most significant drawback of the Victorian legislation for appointing a supporter is that the appointment is not an enduring one in that the appointment lapses once the person loses the ability to understand and consent to it. We believe this should be rectified, at least to give the opportunity for the person to choose between making an appointment that does end in this way, or instead appoint an enduring supporter – so that the appointment does not cease when the person making it loses the capacity to consent to it.[255] As Keeling might argue,[256] the current Victorian design reflects a 'thin' conception of autonomy (where autonomy always prevails over any other value) whereas a richer conception of autonomy would include being able to choose greater permanence in order to avoid being subject to a less palatable imposed guardian. At a practical level, in the absence of an option of appointing an enduring supporter, when a Victorian-type non-enduring appointment lapses, the reality is likely to be that any enduring power of substitute decision-making will be activated. And if there is no enduring power of attorney, then a guardianship or administration order may be sought (and likely granted). The perverse result is that more people will have a substitute decision-maker and at an earlier point in life than otherwise might be achievable if the option of an enduring supporter were to be introduced.

Once such legislative issues are resolved, supported decision-making forward planning should be promoted through education and capacity building measures that are designed not only to improve take-up but also improve the quality of forward planning. In our focus groups, one advocate explained how their organisation was already developing resources to move potential substitute decision-makers' practice closer to supported decision-making.

> …people get appointed as substitute decision makers under Advance Care Directives, and people just think it's an opportunity to make decisions for a person as opposed to with the person. … [we are developing] education tools in relation to Advance Care Directives focusing on substitute decision makers because we want them to be educated and trained in supporting people to make their own decisions for as long as possible, or if they have to make them for them that they focus on the person's wishes and that objectivity… it's an education piece really…if there's no guardianship formal order in place there's no one to account to…it's education and education. (Advocate–generic)

A well-funded and well-designed education program is needed to promote the take up and quality of supported decision-making through forward planning legal instruments. While education is needed for the public at large, it should be targeted primarily at legal and medical professionals, and disability and aged-care service providers, who are often a first point of contact for conversations about advance planning. Particular attention should also be given to tailoring education (including 'templates' and documents) to meet the diverse needs of people from different disability groups as well as those from culturally diverse backgrounds and First Nations peoples.

In Chapter 2, we recommended as the sixth element of the Framework: '**Enabling forward planning** – All legal instruments for forward planning should reflect a principled approach to supported decision-making to minimise the potential for future best interests substitute decision-making remaining as the default option in these instruments. The range of forward planning legal instruments should be expanded to allow for the appointment of supporters and enduring supporters.

Recommendation 8 All Australian legal instruments for forward planning should reflect a principled approach to supported decision-making by being directed by will and preferences, including that when a person with cognitive disability receives supported decision-making from an informal or formally appointed decision supporter enabling them to make clear their advance wishes, these wishes should be respected.

8.1 State and Territory laws should be reformed to offer the option for people to self-appoint a legally recognised supporter for decision-making (as in Victoria). However, consideration should be given to setting the lowest possible level of understanding needed for such appointments and to providing the option of appointing enduring supporters.

8.2 Create and widely disseminate 'templates' for forward planning that align with principles of supported decision-making and allow for recording statements of will and preferences.

8.3 Develop and deliver education programs – both for the public at large, and targeted at legal and medical professionals, disability and aged care support workforce – about the benefits and best practice for supported decision-making through forward planning.

8.4 Give particular attention to adapting forward planning legal instruments, templates and education for the needs of diverse people, by disability type and severity, and for people from diverse cultural background and First Nations people.

8.2 Adequate funding

The right to supported decision-making encapsulated in the CRPD lies at the heart of most aspects of design and implementation of supported decision-making programs and frameworks. The CRPD involves two different but complementary types of rights: civil (like the right to freedom from torture), and the 'socio-economic rights' (like the right to health). These rights are intertwined but differ in terms of their cost. Securing civil rights is not without some economic cost (such as the cost associated with banning and then enforcing a ban on torture), but it is socio-economic rights which need considerable access to resources (such as access to reasonable quality healthcare) and carry significant cost implications.

A very serious weakness of much debate about supported decision-making is that proposed reforms lack attention to questions of resourcing. Supported decision-making involves both civil rights as freedom from protection against denial of autonomy in the form of substitute decision-making, and socio-economic rights as access to support for decision-making. Little or no progress is likely from merely abolishing laws or programs that deny agency and autonomy, such as guardianship and other substitute decision-making, without providing access to supported decision-making. It is the latter that is more resource demanding. Like ensuring the 'freedom' of the homeless not to sleep under bridges,[257] it is the ability to harness resources that determines whether a right is real or merely notional.

Lack of adequate funding to resource all elements of a supported decision-making framework – best practice capacity building, oversight and monitoring and building social networks – was consistently raised by focus group respondents. Some pointed to the potential of existing agencies, both government and non-government involved in supported decision-making, but also to the limited resources available to further this work.

As already discussed in other sections of this Report, respondents were wary of introducing programs, standards or monitoring of these without sufficient resources. Poorly resourced programs were seen as generating more harm than good. Participants pointed out repeatedly the dangers of single informal supporters and of endorsing informal substitute decision-making practices which had the potential to be as restrictive as formal guardianship and perhaps even more so as it might lack formal oversight.

> complicated though when the person abusing them is their supporter. (Advocate–generic)

> Article12 CRPD is tricky – not only guardianship that can rob people of personhood, but quasi-informal guardianship by families and service providers. (Advocate – disability)

Respondents also identified the potential for supported decision-making to be misinterpreted and for simplistic or misguided notions of autonomy to lead to neglect.

> And it's too easy for staff to say, "would you like to go out or would you like to stay home?"

> And Ned's sitting comfortably in the wheelchair, in his armchair watching some movie or some inane stuff on YouTube, and he's going to say, "Oh, I'll just stay here, thanks," because he doesn't like change and change is a bit harder for him than for other people. So, you can't present it like that. (Family–disability)

These concerns flag the importance of oversight mechanisms being built into and funded within existing legal and statutory offices. These additional costs need to be factored into developing a successful supported decision-making framework.

There is also risk that supported decision-making will be used as an excuse for cutting costs in other areas of service provision. Respondents noted the dangers of seeing supported decision-making as a panacea for service system problems and having inflated expectations about what supported decision-making might achieve in furthering the rights of people with disabilities.

While the benefits of successfully implemented supported decision-making are evident, the evidence so far is that providing good quality supported decision-making takes significant time, effort and is far from cost free. 'On the cheap' programs and legislative options for appointment of supporters, involving only the minimal cost of passing the new law, risk the prospect of very few appointments being made and with little to show by way of outcomes even when a supporter is appointed (not least because supported decision-making currently is not an idea that the public grasps or knows how to realise). Unless accompanied by adequate access to the resources needed to make it a reality, support for decision-making will fail.

In Chapter 2, we recommended as the seventh element of the Framework: '**Adequate funding** – Provision of adequate funding is needed to enable supported decision-making to be implemented within and across sectors and jurisdictions in Australia. This bespoke national funding should be separate from service packages in Commonwealth, State or territory schemes such as the NDIS, Aged Care, and other individualised funding packages for support for people with cognitive disabilities'.

Recommendation 9 Provision of adequate funding is needed to enable supported decision-making to be implemented within and across sectors and jurisdictions in Australia. This bespoke national funding should be separate from and additional to, reliance on funding from service packages in Commonwealth, State or Territory schemes such as the NDIS, Aged Care, and other individualised funding packages for support for people with cognitive disabilities.

9.1 A comprehensive cost-benefit analysis, accounting for the full cost of implementing a full package of supported decision-making programs, against an assessment of the benefits to society should be undertaken which should also map which levels and branches of government will bear which costs.

9.2 NDIS, aged care and other State or Territory schemes for individualised packages of funding for support for people with cognitive disabilities should fund supported decision-making for participants who have no access to informal sources of support.

8.3 Formal strategies for building social connections

As already discussed, both the literature and focus group respondents consistently identified inequities among people with cognitive disabilities in their ready access to unpaid supporters who are core to supported decision-making. As several respondents remarked, the perspectives of those without social connections are seldom heard in debates about supported decision-making.

> We're interested in that person who is really super-quiet and is no problem to anybody, because maybe that person doesn't have any family, and has needs that are just being ignored…. (Advocate–disability)

In the case of people with cognitive disabilities associated with intellectual disability, acquired brain injury or mental health, the literature contains very little evidence of effective strategies for building and maintaining social connections for those without a family member who can act as the foundation stone.[258] Among focus group respondents there was also a sense that there was very little real evidence about successful strategies or costs of this type of work. Initiatives that were identified were those of family-based organisations and tended to rely on a person already having a core supporter around whom a network could be generated.

> Need more work on how to find people to be supporters. (Professional)

> You can have a circle of friends… It has to commence with the family or someone who's extremely involved and fond of the individual. Paid staff cannot play that role. It is important for Dave he knows the difference between paid staff and friends… But a paid support worker with a dedicated role could absolutely help build a circle of support – but not be part of it. (Family–disability)

> Have to have a core key person that will then build a network around them and maintain the network – in the long term doesn't have to be expensive…built around facilitator of networks around a person – doing a few hours a month. Takes longer to get them up and running but once established, not a lot of hours. (Family–disability)

In the case of people with dementia, the issue is more often one of declining social connections as friends and family age and die. While social connections are a key to their wellbeing, little attention has been paid to rebuilding social connections for people in later life. Likewise, a focus on building social connections from early age could potentially help realise long term benefits, however there is little evidence to support this.

8.3.1 Are microboards a potential strategy?

NDIS policy currently allows funding for setting up a microboard, though not on-going running costs (such as the time of board members). Whether formally constituted microboards were one useful mechanism for building networks from scratch was raised by respondents, but the requirement for a minimum number of members was seen as an obstacle.

> could be where micro board needed – legal entity – but needs to be wound up if less than 5 or 6 people– needs a commitment. (Family–disability)

The focus group responses suggest that the currently fashionable endorsement of microboards as a vehicle for realisation of supported decision-making may be oversold. Microboards were pioneered in the western Canadian province of Manitoba in 1984 but popularised in British Columbia as Vela microboards for people with intellectual disability.[259] They draw on elements of friendly societies, cooperatives and community associations – all designed to make cheaply accessible to average citizens the advantages associated with having a separate legal identity (corporate legal personality) but without the expense, need for legal advice or other complexities of setting up a company.

Microboards can lay claim to four advantages over informal networks of support: (i) greater accountability and continuity;[260] (ii) building social capital;[261] (iii) 'succession' planning for when ageing families are no longer able to assist; and (iv) as a person-centred way for others to manage someone's individualised funding.[262]

Microboards take very many forms, and as an extensive review in Nunnelley's report for the Law Commission of Ontario suggests, they are all forms of 'personal support networks'.[263] However it is as an alternative way of helping people to realise their will and preferences in 'self-managing' tailored funding packages that they have the greatest appeal.[264] In an Australian context, this would be in serving as an alternative to the current powers of a NDIS 'plan' or a Centrelink 'payment' nominee, though the Canadian experience suggests this would appeal only to people with an intellectual disability.[265] The same is true of any attraction of microboards as a vehicle for succession planning as existing family supporters of persons with an intellectual disability age and die. This overlaps to a degree with the role intended to be played by Australia's poorly designed and thus considerably under-used special disability trusts.[266]

There are both benefits and drawbacks of microboards.[267] The supposed greater accountability is heavily contested,[268] and the symbolism of corporate-faced 'personalisation' of support is, to say the least, somewhat jarring.[269] Succession planning is a much contested goal (paternalistically assuming that this is necessary rather than a product of the person's will and preferences) and in any event it can better be promoted in other ways.[270] Microboards have been found to hold little appeal for people with mental illness, for whom private planning options of advance healthcare directives or supporter appointments better attune to aspirations of maximising control; or for people with ABI who are more likely to already have circles of like-age informal partners/supporters; or for people with a dementia struggling to find a single supporter, much less a pool of people.

The advantages conferred by having more than one supporter (that there are several watchful eyes to help protect against abuse) can be obtained in several more informal ways, short of setting up microboards.[271]

There is nevertheless a very significant gap in evidence about costs and strategies for building and maintain social connections for people with cognitive disabilities as a means of combatting social exclusion and facilitating supported decision-making.

In Chapter 2, we recommended as the eighth element of the Framework: '**Strategies to build social connections** – Strategies to build social connections of people with cognitive disabilities who are socially isolated should be a priority investment in supported decision-making programs and initiatives.'

Recommendation 10 Strategies to build social connections of people with cognitive disabilities who are socially isolated should be a priority investment in supported decision-making programs and initiatives.

10.1 A comprehensive research program to understand how to build social connections for people with cognitive disabilities who do not have existing strong family or informal relationships should be funded as a priority.

10.2 Demonstration programs to build lasting and robust social networks of people with cognitive disabilities who are socially isolated should be funded and evaluated as a priority.

Chapter 9. Barriers to implementing the Framework

Across the world there has been much less progress developing supported decision-making frameworks than anticipated following passage of the CRPD. This lack of progress is despite the success of many pilot programs and a burgeoning body of scholarly literature and law reform reports.[272] This chapter considers the question of barriers that exist to implementing a supported decision-making framework such as that we are proposing. We draw on the perspectives of the respondents in our fieldwork and the rather limited international literature on this issue.

Many of the barriers are associated with the difficulties of creating the prerequisites for supported decision-making some of which are captured in the elements of the proposed Framework as discussed in earlier chapters. They included: divergent understandings; the complex interfaces across systems and levels of government; uncertain demand and acceptability; the scale of funding needed; workforce issues, the limited risk appetites, and maintaining fidelity of supported decision-making and inclusive practices of co leadership.

9.1 Divergent understandings of supported decision-making

Knowledge about supported decision-making as a concept remains at a formative stage in Australia, despite debate among advocates, academics and the disability sector over the last 15 years. This leads to uncertainty and detracts from broad based unequivocal support for its implementation.

Chapter 1 discussed fundamental differences between a binary approach to supported decision-making and the principled approach. The interchangeable use of these two approaches and lack of clarity about supported decision-making in public documents such as that issued recently by the NDIA[273] highlights the lack of a common understanding about the meaning of supported decision-making and its application particularly for people with more severe cognitive impairments. Fieldwork respondents also put forward views that supported decision-making was not widely understood and pointed to the unevenness of knowledge between sectors.

> …there's a part of the disability sector that uses the terms, and then the vast majority of people with disability themselves, and the providers and the NDIA and everybody else, this is all foreign to them. (Advocate–disability)

> ...older people's human rights around decision-making get dismissed much more quickly than in the disability sector. (Advocate–generic)

Another common misconception is equating supported decision-making with advocacy. For example, some focus group respondents moved almost imperceptibly between talking about supported decision-making and advocacy,

> a cohort needs funding for independent advocate to assist major decisions – not just menu choice, but hard stuff – for isolated people without families. (Advocate–disability)

Notably, the DSS pilot for NDIS participants was contracted to advocacy organisations in each State, rather than Offices of the Public Advocate or disability service providers both of whom are experienced in providing different types of decision support. This is not to suggest that advocacy organisations are not suited to supported decision-making, but simply that the two are different. The literature has not addressed differences between advocacy and supported decision-making. However, as the quote above illustrates, advocacy is significant in securing the rights of those without informal social connections beyond service systems, and there are subtle similarities and differences between supported decision-making and advocacy.

Focus group respondents saw elements common to both as: independence from service systems and skills such as listening to the person, ensuring awareness of options and making information understandable. However, the distinction between the two was summed up by a self-advocate,

> Supported decision-making is when I ask someone to help me make a decision – Advocacy is someone representing me. (Self-advocate)

While advocates might support decision-making it was not seen as core to their work, and they were unlikely to have time to build the relationships necessary for good supported decision-making or to develop a person's own confidence and skills for decision-making. Similarly, advocacy could be part of supported decision-making but was not a central role of decision supporters. A key difference was seen as when a decision was made. Advocates' involvements in decisions were more likely after decisions had been made by the person themselves or by others at a time when the focus was on implementing or challenging it.

> A lot of advocacy is also trying to help the person to self-advocate, but with advocacy people know the decision and often make the decision. They just want assistance in getting their way. (Advocate–carers)

Advocacy is more likely to occur at a time of crisis and only involve a short-term relationship with the person whereas supported decision-making often requires a longer-term relationship. Some respondents thought advocacy needed more knowledge of service systems than supported decision-making, while in contrast knowledge of the person was core to supported decision-making.

> …decision support is about the process of making decisions, and advocacy is about addressing issues and taking action, but beyond that, I think they're very closely related. …I think decision support is more about focussing on the person and where they're coming from, and what they want, and advocacy is more about how we get the system to work with what we need for the person'. '…in our mind, advocacy is pretty much issue specific – so domain knowledge is very useful – to resolve an issue. SDM is more client focused on what you need to know about the person and what they prefer. The need is ongoing. (Advocate–disability)

As we have already flagged, there is also very little knowledge about the applicability of supported decision-making to the collective rather than individual approach to decision-making, for example as referred to by some representatives of First Nations communities. The significant gap in evidence about alternative, more culturally meaningful ways of translating the underlying intentions of supported decision-making to First Nations people creates a significant obstacle to universal implementation of supported decision-making.

It was also apparent in our fieldwork that there is some confusion between the collective approach to decision-making reported as preferable within First Nations communities and a supported decision-making approach that relies on an informal or formal group of supporters, but which still retains an arguably individualistic focus on the ‘decision maker’.

> Need to recognise collectivist decision-making – for example, microboards, but also Aboriginal and Torres Strait Islander and CaLD communities. (Professional)

9.2 Managing complex interfaces across service systems and levels of government

The earlier chapters of this Report explored the interrelationship between supported decision-making and different service systems, sectors and levels of government, illustrating that it cannot stand alone. The complexity of policies needed to take multiple system interfaces into account poses many potential barriers to implementing a universal and national Framework for supported decision-making. These issues were very apparent to focus group respondents. They saw that the patchiness of knowledge and embrace of supported decision-making across sectors compounded difficulties of implementing a national, cross-sector, consistent State and Territory approach to supported decision-making.

The federal system of government itself is a potential barrier to implementing supported decision-making. Commenting on federalism respondents highlighted a,

> Need to look at aligning regulation across care systems while also acknowledging the need for some difference…. Very hard to have oversight across different sectors re abuse and neglect because rules and reporting are different, state and federal etc, different restrictive practices regimes. (Advocate–carer)

While in theory the Commonwealth could enact overriding legislation based in the external affairs or so-called ‘treaty power’ in section 51(xxix) of the Constitution, this is unrealistic for several reasons. First, because the national government is too distant from day-to-day administration of programs and has limited experience and a poor record of delivering human services. Second, because even the broadest interpretation of constitutional powers would leave most of the interrelated State and Territory services and institutions beyond reach of any new Commonwealth legislation leaving intact the existing fragmentation, lack of uniformity and even outright competition and conflict of policies relevant to supported decision-making. The reason is that the Constitution splits relevant responsibilities between the Commonwealth government and the State/Territory governments.

The NDIS offers an excellent illustration of a complex interface that will have to be tackled, and the way people with cognitive disabilities are caught between the provision of different government and service systems. Decision-making by participants about the size and appropriateness of their NDIS plan and its management is governed by Commonwealth laws, which while imperfect, better reflect supported decision-making principles than do the laws of most States/Territories. For instance, the person is presumed capable; and a 'nominee' can be appointed if the person lacks decision-making ability and it is not possible for them to make decisions for themselves. While NDIS nominees are presently given powers inappropriate in the context of supported decision-making,[274] the NDIA consultancy paper does recommend confining the use of existing or reformed powers to an absolute last resort.[275]

The interface problems for NDIS participants are that they may be engaged with State or Territory responsibilities for health, disability, child welfare or guardianship and financial/property administration. Thus, in addition to any NDIS nominee, an NDIS participant may be under an unreformed State or Territory guardianship or financial administration order, or be subject to health default decision-maker provisions empowering others (known variously as 'person responsible', 'medical treatment decision maker', 'statutory health attorney' or 'health attorney') to make health decisions, often according with 'best interests' rather than will and preferences, and as a substitute rather than as a supporter. That clash would be further accentuated by the overdue reform of NDIS nominee powers in the way we and the ALRC propose.

The multiple interfaces between levels of government and service systems raise other important issues, such as where the costs of supported decision-making should lie. For example, the funding of support as a 'reasonable and necessary' part of an NDIS package relies on satisfying section 34(1)(f)(i) of the *National Disability Insurance Scheme Act 2013* (Cth) by showing that it is 'not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered as part of a universal service obligation'. It is arguable that the NDIS should fund participants to access good quality supported decision-making as part of their individualised funding package as supported decision-making is a reasonable and necessary disability-related need. Following the same line of argument, should this funding extend to capacity-building for service providers to also be funded by the NDIS as well as civil society supporters such as family or friends? If this were to be the case, how should the amount be decided? By the planners (i.e., paternalistically) or should it be an option for all participants with cognitive disability and if so is the percentage of a package devoted to supported decision-making capped or at their discretion? Similar questions could be posed in aged care, particularly regarding home care packages, or provision of supported decision-making in residential care.

Alternatively, one might argue, as has occurred in the Administrative Appeals Tribunal (AAT), that supported decision-making for NDIS participants should be conceived as a generic entitlement for all people with cognitive disabilities whether they are NDIS participants or not. As such it falls outside of the NDIS, especially given that NDIS participants will also require supported decision-making in the context of a wide range of service systems. Boundary lines such as these are frequently contested on review in the AAT[276] and are just one illustration of the complexity of the barriers to implementing supported decision-making. Again, similar issues arise in aged care.

9.3 Uncertain uptake and acceptance

Low demand for supported decision-making among people with cognitive disabilities and their unpaid supporters, and limited acceptance by institutions or service organisations also pose barriers to implementation. Receptiveness to supported decision-making is greater within some disability groups than others, though individual members of any group cover the full spectrum from enthusiastic adopters to outright rejecters.[277]

A person's age; level of knowledge of supported decision-making; past experience of informal supported decision-making; future expectations; views and values about individual and collective decision-making, and cultural and individual attitudes to authority, are among the multitude of factors contributing to an individual's receptiveness or otherwise to supported decision-making. For example, a person with mental illness may not see a need to organise support for an episode of cognitive impairment that they neither anticipate nor wish to believe that they will experience ever again. Or someone with an early-stage dementia may place less weight on preserving their autonomy compared with protecting their finances and healthcare provision.

Uptake of supported decision-making is mediated by knowledge about it, and the success (or not) of capacity building and changed attitudes of those who act as gatekeepers to supported decision-making (legal, finance, health and welfare professionals to name but a few). There is a long way to go in this regard. For example, studies have found that irrespective of the source of information or nature of disability involved, plenary guardianship is discussed most frequently while alternatives are rarely canvassed, and supported decision-making least of all.[278] Holler and Werner's Israeli study exemplified the limited impact that passing new supported decision-making laws has if professional gatekeepers such as social workers have little understanding or confidence in it, and continue to direct people into guardianship.[279] While that study focused on social work professionals, it can be expected that this 'channelling' effect may also be occur when family, friends or community members are the primary source of advice and have little knowledge or confidence in supported decision-making.[280]

A further barrier to uptake for supported decision-making may be the gravity of the crisis situations that characterise most guardianship applications. The severity and intractability of those crises has been found to rule out appointment of a supporter. Thus, as a Victorian pilot demonstrated, crisis situations made establishment of a new relationship of support completely unviable even when a person might otherwise be 'desperately in need' of such support.[281] As previously discussed, the social reality of the population of people subject to guardianship, including those who may have had a supporter but whose capacity to continue in that role has been exhausted, may explain why reportedly no supporters (ie 'supportive guardians') have yet been appointed by VCAT despite the 2019 legal reforms enabling this. There are lessons for other jurisdictions from the Victorian experience. Certainly, those reforms have succeeded in ensuring that will and preferences are at the centre of tribunal decision-making, but other unreformed jurisdictions have also incorporated the principles of supported decision-making values to a more limited extent.[282] Path dependence theory showing the resistance of existing institutions and processes to change,[283] highlights the difficulties and limits around the degree of institutional change able to be achieved in the short term. However, the Israel reform demonstrates for example, the lack of success with supported decision-making reforms when they are insufficiently engaged with guardianship systems.[284] This suggests Victoria's approach of incorporating supported decision-making as the dominant preference within and alongside reformed guardianship may prove more effective.[285]

Targeting particular populations with potentially high and long-term demand for supported decision-making, such as NDIS participants, may lead to a higher take-up at lower overall program cost than for a generic educative or recruitment program directed to the public at large. That was the rationale of the OVAL project in Victoria, but it encountered some unexpected if understandable barriers intrinsic to the dynamics of NDIS administration and service providers. These included workers having too little time to identify and recruit participants and service providers' fears that the appointment of a supporter might result in a change of service provider.[286]

Even in the disability sector, where supported decision-making has gained most exposure, respondents raised questions about the commitment of service providers to supported decision-making and their willingness to promote it. The reluctance to embrace supported decision-making was seen to stem from the potentially conflicted position of service providers in respect of decisions made by the people they supported or when a person they supported and family members had differing opinions.

> ...if an adult is surrounded by providers and others who have a vested interested in keeping them within their clutches then they won't be encouraged to do supported decision-making – vicious cycle of vulnerability. (Advocacy–disability)

> Service providers can be reluctant to challenge family where family are undermining the person. (Advocate–disability)

9.4 Scale of funding needed for implementation

Historically Australia has had a longstanding commitment to recognising government responsibility for some aspects of decision-making that would fall under the umbrella of supported decision-making if a framework of the nature recommended in this Report were to be implemented. For example, through the statutory Offices of Public Trustee the government meets some of the costs of managing property and finance of people on low incomes when encountering cognitive decline. Also, through tribunals and Offices of Public Advocates and Public Guardians governments have established cost free and accessible guardianship and administration for people with cognitive disabilities, as well as providing watchdog and accountability structures.

The costs of implementing supported decision-making are likely to be significant and potentially an impediment to its the development. For example, as discussed in earlier chapters, capacity building at individual, system and institutional levels is fundamental to successful implementation but will need significant funding over a considerable period of time to achieve the required knowledge, attitude and skill changes. An entrenched paradigm of paternalism and 'best interest' substitute decision-making among professionals will be difficult to shift to one of support for expression of the agency and autonomy of the person with a cognitive impairment.[287] Added to this, few capacity-building programs have been evaluated to assess the direction, degree or durability of claimed success in increased realisation of the will and preferences of people; and those that do have an evidence base have not yet been shown to be universally effective across disability groups or individual circumstances.[288]

Respondents also drew attention to the critical role that support networks played in supported decision-making and the substantial investment needed to build and nurture networks for those who were socially isolated and without informal support of any kind. Respondents also perceived there was very little evidence about how this could be done for people without strong family support or on the costs involved. While respondents pointed to family-based organisations which had developed strategies to build circles of support and microboards, drawing on international work from Canada, no parallel work was identified for those without family members. As respondents said,

> We don't yet know how to build informal networks. (Advocate–mental health)
>
> Natural relationships are the best, keep people safest – need paid support though to build those relationships – long-lasting relationships – NDIS is all about inclusion. (Professional)

This suggests that investment will be needed in research and demonstration programs to develop evidence about building social connections for isolated people, if supported decision-making is to be successful.

The barriers posed by lack of resourcing are not confined to direct supported decision-making programs or process. Rather, they extend to institutions integral to supported decision-making which if not adequately resourced may pose indirect barriers to implementation. For example, guardianship tribunals need adequate resourcing to serve the important gatekeeper role of ensuring that guardianship orders are made only when they are the least restrictive alternative and where all informal (or any formal) support options have been exhausted. Through careful choice of appointees and crafting of orders,[289] they can also seek to ensure that supported decision-making choices and principles are maximised even when substitute decision-making powers are conferred. Even in the absence of a citizen willing to accept appointment, capacity building training in supported decision-making demonstrates that orders appointing the Public Trustee or Public Advocate can be administered in ways which maximise autonomy and respect for principles of supported decision-making.[290] But fulfilling such roles as part of a supported decision-making framework would need a boost to the funding of those bodies to ensure that staff have adequate time and 'space' for getting to know the person and for reflection on the decisions being made. In a similar vein, research shows that inadequate tribunal funding inevitably leads to unduly compressed guardianship tribunal hearing times.[291] Under-funding of statutory offices of the Public Trustee, Public Guardian or Public Advocate results in case managers being burdened with too many people and too little time to properly apply supported decision-making principles in their work.

If implementation is left under-resourced, supported decision-making can be expected to be done rather poorly, to degrade in quality over time, and lead to proliferation of instances of abuse and neglect. Care will also need to be taken in operationalising a supported decision-making framework to ensure that any savings incurred as one part of a reform (such as reduced demand for guardianship) are reinvested to achieve results in other parts (such as capacity building for supporters and development of appropriate monitoring and oversight).

Respondents were not optimistic that adequate resources would be forthcoming and reflected on the current funding pressures experienced by many agencies that would be central to the implementation of supported decision-making. For example, one respondent drew attention to the unattractiveness to the NDIS of investment in a new program when it was already under significant cost pressure.

> But it won’t suit the NDIA if those recommendations are expensive to the NDIS, if it requires additional funding. (Advocate–disability)

Many also reflected on the underfunding and consequent overloading of the current infrastructure including Offices of Public Advocates or Guardians, which though well placed to further supported decision-making systems, could only do so with additional funding.

> Systems such as public guardians are inadequately funded. Guardianship processes can be improved, but basically the architecture is pretty reasonable. (Advocate–mental health)
>
> OPA caseloads are too big, so they don’t have the time. (Advocate–generic)
>
> My view is that with supported decision-making the OPA is ‘in crisis’. They are unable to address guardianship requests in a timely way, there is a long wait for guardians, they are well under-resourced. As an advocacy service we might look to the OPA to better understand decision support but ‘they’re struggling to implement the law really’…There is a risk in trying to do supported decision-making in haste – could be a disaster for some clients. (Advocate–disability)

9.5 Workforce issues

Supported decision-making is highly sensitive to the contexts in which it is embedded and for many people the context will include paid service providers, particularly in the disability and aged care sectors. The influence of these service providers can potentially achieve much in developing supported decision-making. Their staff are well placed to promote awareness of supported decision-making principles among fellow staff, the people they support, their families and other stakeholders who are ‘at the coalface’ of service delivery. Through appropriate policies and procedures, support models and uptake of best practice training and resources, the aged care and disability workforce can be enabled to provide supported decision-making for day-to-day decisions. Finally, this workforce is often also well placed to detect and draw attention to signs of abuse or neglect, particularly when support is coordinated within multi-disciplinary teams who are able to share information.[292] In a workforce specialised in providing support for people with disabilities to realise their goals, we find a cohort who might be equipped with the skills and resources to progressively give expression to the ‘best practice’ element of this Framework. However, in practice there are several barriers to realising this outcome.

The ‘care sector’ has been under-resourced historically and particularly in recent years.[293] Population projections show an expected increase in age-related disability, which has not been matched with sufficient expansion of this workforce.[294] At a market level, workers in the aged care and disability sectors are paid poorly and often only cursorily trained. Even professionally qualified staff rates of pay are not comparable to similar roles in the general health sector. This makes it difficult to attract and retain sufficiently skilled staff. High rates of staff turnover hinder efforts to keep staff trained even in core competencies, and leave managers focused on filling shifts, rather than implementing best-practice support. This issue has been exacerbated by the COVID-19 pandemic. The result is that training programs and the ongoing resourcing of best practice supported decision-making is often seen as an unaffordable luxury.

9.6 Limited risk appetites and maintaining fidelity of practice and co-leadership

As discussed in Chapter 7, for all supporters, consistently adhering to the principles of supported decision-making is an onerous, emotionally challenging, skilled and complex task. These challenges are compounded by risk and enabling people to experience the dignity of risk. For supporters, there is a constant need to balance rights, risks and practicalities, and judge immediate preferences against long term priorities. The scale of the task of developing supporters’ skills must not be allowed to undermine fidelity to principles of supported decision-making and best practice. Embedding these into the culture of organisations, should not be underestimated. Likely barriers are tendencies for short term rather than programmatic funding for capacity building programs, and rushed implementation plans that demand immediate change rather than recognizing the length of time needed to achieve deep and lasting rather than superficial change to skills and culture.

It will demand long term work for example, to change the language of well-established programs such as Citizen Advocacy, which do excellent work in building long term relationships between people with and without disabilities, and to realign such programs with the principles of supported decision-making. Similarly, shifting practice in the aged care sector, where a person’s preferences might change as support needs increase, and where a best interests approach is entrenched, also will take time, resources and determination.

> And then there's a balance between what the perceived preference is now with the risk and the best interests that has to be weighed up too. So, it feels like supporters, in this field, don't want to give up the best interest element of decision support. (Advocate–aged care)

The limited risk appetites of governments were also seen as impediments to implementing supported decision-making by focus group respondents. They remarked on what they saw as an increasing risk averse position taken in the aged care and disability sectors.

> …it comes down to that risk aversion, "We don't want to get ourselves into trouble, we need to do whatever we can to make sure that this person stays safe," but then in doing so you're not giving that person the dignity of risk to do something, to make a decision that might not really be in their best interests, but it's what they want to do, like going outside unattended, you know….I mean the locked door thing, that comes up so often, "We lock the door because if they go out into the garden they might trip and fall and then they'll end up in hospital," "Well, they're miserable stuck inside and not being able to go out and sit in the garden." (Advocate–aged care)

> Challenges with risk – especially for statutory substitute decision makers – pendulum swings in terms of public/political tolerances and with the Anne Marie Smith case tolerance for allowing risk has reduced. (Advocate–generic)

They also warned of the dangers of allowing risk to dominate and potentially compromise the design of supported decision-making programs, as the majority of situations were unlikely to revolve around these issues. This echoes our recommendations in Chapter 1 that any need for substitute decision-making for reasons of significant risk, are likely to be rare.

> Don't get stuck at the pointy end of high risk because you 'lose sight of the fact that like 95 per cent of decision-making may not sit in that space'. The culture needs to be enriching, not about containing or minimising risk…. You need to have systems to protect people from the unscrupulous supporter – but the system needs to be designed with the 95 per cent in mind – and have safety nets in place for the minority. (Service provider)

As focus group respondents suggested, there were concerns that some services providers might adopt a minimalist or 'lite' approach to supported decision-making which might satisfy standards but would fail to have any substantive change in the way people were supported to exercise their rights.

> There is supported decision-making 'lite' where workers try and give simple choices – Weetabix or porridge but not enough…Providers are very traditional – but they can tick boxes for quality audits re pseudo choice –eg, menu and day program …But providers don't seem to really sit down with the person and work out their choices. (Advocate–disability)

Determining what if any progress is made by supporters in acquiring and using new skills in the individual instance is hard to assess,[295] and the risk of miscarriage due to supporter's values being applied to the person supported are real.[296] As discussed in Chapter 7, there will be an ongoing need to monitor and assess the impact of initiatives to change practice and culture where barriers to supported decision-making currently exist.

There are also significant challenges in implementing co-leadership of supported decision-making initiatives by people with cognitive disabilities. Their inclusion in leadership and design of research, policy and programs only goes back to the early 1980s.[297] As a group their perspectives have often been overshadowed by those with disability but without cognitive impairment, as occurred in the design of the NDIS.[298] There remains much to be learned about the practices of inclusion of people with cognitive disabilities in both advisory and co-design initiatives and to understand how processes should be adapted to create inclusive environments and the types of skills and strategies needed to provide effective tailored support to individuals to enable their participation. A further challenge in the context of supported decision-making is to ensure that the perspectives of people with more severe and profound cognitive disabilities are included, given the very limited focus on this group to date. For this to occur, significant collaboration will be required between people with lived experience of cognitive disability, supporters of people with severe cognitive impairments, representative organisations of people with cognitive disabilities and caregivers, as well as researchers experienced in this field.

In Chapter 2, we recommended as Principle 9 the Framework: '**Co-leadership of people with cognitive disabilities** – People with cognitive disabilities and supporters of people with severe cognitive disabilities should lead consultation and design processes for supported decision-making reform and initiatives'.

Recommendation 11 People with cognitive disabilities and supporters of people with severe cognitive disabilities should lead consultation and design processes for supported decision-making reform and initiatives.

11.1 Further research is needed to ensure people with more severe or profound cognitive disabilities are not excluded from co-leadership and co-design efforts. This extends to research about the practices of inclusion of people with cognitive disabilities in advisory and co-design initiatives to understand how processes should be adapted to create inclusive environments and the types of skills and strategies required to provide effective tailored support to individuals to enable their participation.

11.2 The principles and elements of the Framework were derived through a process that involved extensive consultation with people with cognitive disability, advocates as well as professionals. However, this Framework should be debated, and refined further if necessary, in a process that involves co-leadership of people with disability and supporters of people with severe cognitive impairments. A reform agenda taskforce co-led by people with disability, including disabled people's organisations, the Offices of Public Advocates and Public Guardians, carer organisations, disability service providers, NDIS, State, Territory and Commonwealth Government disability ministries should be established for this purpose.

9.7 Conclusion

We have identified that significant barriers exist in multiple sectors and at multiple levels to the implementation of supported decision-making in practice. However, the identification of barriers is the first step to enabling action within professions, organisations, sectors and government departments to plan to reduce or remove these barriers in the long term. The final chapter of this Report focuses on key issues relevant to implementation of the supported decision-making Framework we have proposed.

Chapter 10. Summary and conclusions about implementation

In previous chapters we have identified the principles and essential elements of a supported decision-making framework. In this chapter we summarise each of those principles and elements, highlighting what it might take to put such a framework into practice. We conclude by explaining why it is important to treat implementation as a comprehensive piece of social policy reform.

10.1 Diversity, dignity, equity and best practice: a principled approach to supported decision-making

Supported decision-making for people with cognitive disability helps to realise and fulfil their rights to autonomy and thus their socio-economic rights such as to participate in society. The evidence also demonstrates additional benefits of supported decision-making such as increased self-confidence and sense of belonging, improved decision-making and self-advocacy skills. Among respondents in our own research there was consensus that by involving more people in providing support for decision-making, people with cognitive disability can build social connections, and be better protected against abuse and harm. However, these positive outcomes depend on the way supported decision-making is conceptualised and then brought into practice.

In the proposed Framework, supported decision-making is not the binary opposite of substitute decision-making, rather it takes a principled approach that recognises a continuum of forms of support designed to maximise a person's autonomy in decision-making. These range from supporting a person to make decisions based on their stated will and preferences, through to substitute decision-making that is centred on supporters' best interpretation of the person's will and preferences, and in very limited circumstances substitute decision-making centred on a person's right to personal and social wellbeing.

Operationalising this Framework for supported decision-making will be different in different contexts and for different groups of people. However, the overarching principles of the Framework need to be universal, encompassing all people with cognitive disabilities, all service sectors and jurisdictions across Australia, and all types of decisions. The first four principles mirror those recommended by the ALRC; the other five are additional. Principles 5 to 7 reflect the recommended principled approach to supported decision-making that includes all people with cognitive disability, no matter how severe, and recognises the significance of risk to both supporters and those who are supported. Principle 8 addresses inequities in access to supported decision-making and recommends that those experiencing disadvantage in access to support for decision-making should be given priority in new programs. These include people without strong and resourceful family or informal networks – without any relationships outside service systems, and those with severe cognitive disabilities for whom expression of preferences and participation was the most difficult. Principle 9 is focused on co-leadership by people with cognitive disabilities and the supporters of those with severe cognitive impairments. This is important to comply with the core ethical disability rights principle of 'nothing about us without us'. Co-leadership by people with disability, together with participation by peak (and some smaller/specialised) non-government agencies, is needed to give legitimacy and integrity to the implementation of supported decision-making. Co-leadership is also crucial to gaining the wide popular appeal needed, given that so much of the reform agenda is pitched at informal family and community settings and support practices by ordinary members of the public.

Principle 1: The equal right to make decisions

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

Principle 2: Support

All people who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will, preferences and rights

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

Principle 4: Safeguards

Laws, legal and policy frameworks must contain appropriate and effective safeguards in relation to interventions for people who may require decision-making support, including to prevent abuse and undue influence.

Principle 5: Principled approach to supported decision-making

A principled approach to the concept and practice of supported decision-making should be adopted that keeps an individual's stated or perceived 'will and preferences' at the centre of decision-making. This approach recognises the realities of the practice of providing supported decision-making, particularly for those with severe cognitive disabilities.

Principle 6: Best interpretation of will and preferences

In the very limited circumstances where a supporter has not been able to elicit a person's will and preferences a decision should be based on their best interpretation of what the person's will and preferences would be.

Principle 7: Dignity and risk

The dignity and importance of taking risks is acknowledged and supported. In very limited circumstances, where a person's stated or inferred will and preferences involve risk of serious, imminent physical or financial harm with lasting consequences to themselves (including incurring civil or criminal liability), and that person is unable to understand that risk even with support, substitute decision-making is applied as a last resort with the person's personal and social wellbeing at the centre.

Principle 8: Distributional equity

All supported decision-making reform and initiatives should be premised on the ethical principle of a commitment to distributional equity of access to supported decision-making. Those experiencing disadvantage in access to support for decision-making should be given priority in new programs.

Principle 9: Co-leadership of people with cognitive disabilities

People with cognitive disabilities and supporters of people with severe cognitive disabilities should lead consultation and design processes for supported decision-making reform and initiatives.

Recommendations 11.1 – 11.2 are designed to further this principle:

11.1 Further research is needed to ensure people with more severe or profound cognitive disabilities are not excluded from co-leadership and co-design efforts. This extends to research about the practices of inclusion of people with cognitive disabilities in advisory and co-design initiatives to understand how processes should be adapted to create inclusive environments and the types of skills and strategies required to provide effective tailored support to individuals to enable their participation.

11.2 The principles and elements of the Framework were derived through a process that involved extensive consultation with people with cognitive disability, advocates as well as professionals. However, this Framework should be debated, and refined further if necessary, in a process that involves co-leadership of people with disability and supporters of people with severe cognitive impairments. A reform agenda taskforce co-led by people with disability, including disabled people’s organisations, offices of public advocates, carer organisations, disability service providers, NDIS, State, Territory and Commonwealth Government disability ministries should be established for this purpose.

10.2 The Framework elements

Element 1: Recognising diversity in supported decision-making

Supported decision-making is needed by people with cognitive disabilities, including people with intellectual disabilities, acquired brain injuries, dementia or mental health conditions and psychosocial disability. Although most have some form of cognitive disability – including difficulty understanding and communicating complex ideas – people who need decision support are extremely diverse in the type and severity of their cognitive impairment, and other personal attributes such as gender, sexuality, cultural background, socioeconomic status and other forms of human diversity. These differences demand different approaches to implementing supported decision-making.

These differences impact on people in various ways, including: cognitive capacities and how they change over time (eg, episodic, declining, ongoing); social connections; service settings they engage with (eg, clinicians, aged care services, disability services); histories of living with or without a cognitive disability; cultural expectations relating to autonomy and forms of support; geographical and economic barriers and enablers to access formal and informal support.

The issues for people with different types of cognitive disability intersect with other diverse characteristics, situations and identities. For example, supported decision-making for First Nations peoples with cognitive disability needs attention to: intergenerational trauma; mistrust and suspicion of service systems; cultural biases that characterise service systems; awareness of history, kinship responsibilities, cultural values and beliefs and 'ways of working' in state-led support systems; a cultural incongruence between Indigenous and Western worldviews relating to individualism, collectivism and decision-making; and barriers to accessing support services, such as language, stigma and shame.

Diverse types of programs and practices need to be developed, which follow a shared set of universal supported decision-making principles, but address the different challenges, opportunities, needs and choices of people with disability in their full diversity.

Recommendations 3.1 – 3.3 are designed to further this element:

3.1 Funding priority and specific attention should be given to the design of the suite of measures that aims to further understand how the principles and elements of the supported decision-making framework can be interpreted and applied to culturally and linguistically diverse and First Nations community settings. This should include recognition of informal expressions which expand or refine the intention behind decisions to appoint a supporter or substitute decision-maker and expectations of those supporters.

3.2 It is too early in the development of supported decision-making programs and there is too little evidence about its implementation across diverse groups, sectors and institutional arrangements to be prescriptive about a consistent programmatic type of supported decision-making. There should be continuing room for innovation and for evidence to be gathered about what works, in what contexts, for whom. Nevertheless, all developments should be driven by the application of universal principles of supported decision-making.

Element 2: Interrelationship of supported decision-making with other systems

Supported decision-making must be embedded within existing service and legal systems, with different traditions of decision support that are often premised on substitute decision-making. These include disability services, healthcare, aged care, Centrelink and the NDIS, to name a few. Taking a principled approach means supported decision-making should be embedded not in isolation from, but rather within, existing and potentially reformed substitute decision-making mechanisms including enduring powers of attorney, nominee provisions and guardianship and administration systems. While historically guardianship systems have been set up to facilitate substitute decision-making, the tribunals and other associated bodies such as the Offices of the Public Advocate, Public Guardian and Public Trustee are now beginning to embed supported decision-making practices within their own institutions. Importantly, although guardianship only directly applies to a very small proportion of all people with cognitive disability, these institutions are well placed to promote supported decision-making more broadly in the community and in service settings. They do this through such functions as investigating complaints of abuse and neglect of people with cognitive disabilities, systemic and individual advocacy, and through the community visitor programs for supported accommodation (or wider mandates in jurisdictions such as South Australia).

The NDIS is also an important area for reform. It is premised on a philosophy of choice and control that celebrates autonomy but implemented through individualised funding which can be disadvantageous for people with cognitive disability. Supported decision-making was notably omitted from the scheme in its design, and NDIS policy does not allow funding of supported decision-making in a participant's package.

For supported decision-making to succeed, it must be embedded in a cohesive and inclusive range of government, non-government agency and civil society measures. Change should be sought holistically across programs, laws, systems and social processes. But change must adequately accommodate the interactions and consequences encountered at the interfaces where supported decision-making engages the other, less compatible, systems where substitute decision-making is more prominent.

Any proposals for introduction and expansion of the role of supported decision-making should start with a review of those institutions, people and funding schemes already in the field. They already exist (avoiding the challenge of selling new untested initiatives to sceptical politicians or the public) and they may be capable of being 'repurposed' to a greater or lesser extent. Australia's public funding of statutory bodies engaged in the lives of people with disabilities creates a pool of agency staff and other resources able to be retooled towards providing greater support for decision-making. At the State and Territory level these include guardianship tribunals, accident compensation commissions, and Offices of the Public Trustee, Public Guardian or Public Advocate. At national level they include the NDIA and Services Australia. The transformation wrought for the organisational culture of the Queensland Public Trustee or TAC following decisions to spend funds to commission training, is evidence that legislative or other 'signalling' of a desired direction of change in supported decision-making practice can be quite effective in 'repurposing' human capital where it already exists.

Recommendations 4.1 – 4.8 are designed to further this element:

4.1 Context-specific supported decision-making action plans should be produced for different sectors and institutional settings each outlining a portfolio of legislative and non-legislative measures to improve quality and take up of supported decision-making in that context, while adhering to a shared agreed set of universal principles.All 'unsound mind' provisions in all Australian electoral legislation should be repealed, and strategies put in place to ensure all people with cognitive disabilities are enrolled to vote but not penalised if they choose not to.

4.2 State or Territory laws that enables ‘default’ substitute decision-makers for healthcare decisions should, where necessary, be reformed to ensure that substitute decisions made by the default substitute decision-maker are in accordance with the will and preferences of the person, are a last resort and for the shortest possible time.

4.3 State or Territory laws allowing self-appointment of substitute decision-makers with authority to make decisions once a person is no longer able to make decisions should be reformed to ensure that decisions made by the substitute decision-maker are in accordance with the will and preferences of the person.

4.4 Centrelink payment nominee, correspondence nominee and associated arrangements should be reformed to reflect a principled approach to supported decision-making and ensure that decisions made by the substitute decision-maker are in accordance with the will and preferences of the person.

4.5 NDIS nominee provisions should be reformed to reflect a principled approach to supported decision-making and ensure that decisions made by the substitute decision-maker are in accordance with the will and preferences of the person.

4.6 State and Territory guardianship and administration laws should be reformed in accordance with a principled approach to supported decision-making. New statutory tribunal appointed supporter roles (similar to Victoria) should be implemented but consideration given to the need for a person to consent to tribunal appointed supporters or for decision-making capacity to be restored as a condition of appointment.

4.7 Collection of monitoring data on trends in various types of support, nominee, attorney/guardianship powers should be collated and surveys undertaken to obtain data about informal arrangements. The Australian Institute of Health and Welfare may be an appropriate body to have carriage of this responsibility.

Element 3: Best practice and ethical supported decision-making

Evidence is beginning to build on how supported decision-making can be practised ‘on the ground’ or at the ‘frontline’ by supporters, to give effect to the principles outlined in our Framework in the most effective way. The evidence points to some emerging common aspects of ‘best practice’, such as the importance of knowing the person who is supported, the need to have sufficient time, to tailor communication to the person, and to offer options from which they might choose; and the importance of supporters’ self-reflexivity. Having multiple rather than a single supporter, and having supporters who are ‘independent’ – i.e., free of conflicted interests relating to the outcomes of decisions – are also widely considered as elements of best practice, but not always a realistic possibility for many people who are isolated from informal or formal support.

To facilitate best practice in supported decision-making, it is important to continue to build the evidence about those practices which are most effective for different people, in different contexts. Evidence gaps, such as those on how the formal standing of supporters impacts the quality of support, need to be filled.

Recommendations 5.1 – 5.4 are designed to further this element:

5.1 The following categories be used to distinguish between supporters:

- Informal unpaid civil society supporters (for example, family, friends, associates, volunteers) with no formal recognition as a decision supporter
- Unpaid civil society supporters with a formal appointment as a decision supporter for all or some decisions (for example, a friend appointed as a legally recognised supporter – ‘supportive attorney’ in Victoria)
- Paid supporters who provide supported decision-making as part of their professional or support role and are monitored by their employer, subject to a code of conduct or professional registration requirements (for example, aged care workers or health care professionals)
- Paid supporters who are formally appointed and recognised as decision supporters (for example, a statutory guardian of last resort adopting a principled approach)
- Paid supporters who have a dedicated role in decision support and who may or may not be formally recognised (for example, an employed decision supporter in a funded pilot supported decision-making scheme).

5.2 A national repository of resources for best practice supported decision-making should be established and actively curated to assess the strength of evidence on which they are based and promote dissemination of evidence informed resources. This would serve as a resource for dynamic communities of practice in sharing knowledge and experiences of supported decision-making generally or for specific groups or sectors.

5.3 Further research is needed on different forms of recognition or legal standing for paid and unpaid supporters, and their impact on the quality of supported decision-making.

5.4 Further research is needed in particular on practice of how supported decision-making can work in the context of people with disabilities with severe cognitive impairments.

Element 4: Capacity building at individual, system, and institutional levels

It is crucial to translate the evidence on best practice to training programs and resources that are widely disseminated to paid and unpaid supporters, and through communities of practice. A broad range of strategies, some with targeted audiences and others more generic, could increase the skills of all potential supporters, assist people with disabilities to know their rights to support, maximise effectiveness of support, raise community expectations about involvement of people with disabilities in decision-making and contribute to cultural change.

Building people with cognitive disabilities' capacity to participate in decision-making is also an important aspect of our framework. This builds on efforts from the 1980s to promote self-advocacy by building capacity of people to understand and speak out about their rights.[299] It also builds on a strong body of research on self-determination from the disciplines of psychology and special education.[300] However, there is a need to build decision-making capacity more specifically, rather than simply accord a broad understanding of rights and self-determination.

Recommendations 6.1 – 6.6 are designed to further this element:

6.1 A key focus in the design of new supported decision-making programs and initiatives should be capacity building of paid and unpaid supporters.

6.2 There should be a focus on capacity building of people with cognitive disabilities that enables development of their skills in decision-making and / or optimal use of available support for decision-making. This is particularly important across the entire life course for people with intellectual disabilities.

6.3 Particular attention should be given to capacity building initiatives that account for the needs of diverse people, by disability type and severity, and for people from diverse cultural backgrounds and First Nations peoples.

6.4 Awareness of supported decision-making and skills in best practices should be built into the NDIS workforce competence framework and core competencies of all professionals involved in health, aged care, legal, financial, human service and criminal justice systems.

6.5 A proactive approach is needed to disseminate capacity building resources, especially to informal supporters. This should include proactive circulation of information about resources through diverse media and networks, and incentives for supporters to actively engage in capacity building programs.

6.6 To move away from a culture of protection to one that enables people to take on and experience risks, all supporters, organisations and institutions involved with people with cognitive disabilities should have access to education about risk enablement and the positive aspects of risk taking to avoid an overly protective approach to all types of risk.

6.7 To increase awareness, understanding and respect for disability rights, and decision-making rights in particular, there is a need for public awareness campaigns and embedding content on disability rights in the education system.

Element 5: Safeguarding, quality assurance and oversight

Supported decision-making often happens in private spaces not open to public scrutiny and in relationships of unequal power. This creates risk of manipulation, undue influence and abuse by supporters. Therefore, safeguards, quality assurance and oversight are integral elements of a supported decision-making framework. Different forms of oversight are needed for formal and informal, paid and unpaid supported decision-making. For paid supporters, safeguarding can be implemented through standards and accreditation of services and workers in the NDIS and aged care sectors, and professional registration and codes of conduct of allied health, medical, legal and financial professionals. Practices such as formal documentation of supported decision-making processes, and scrutiny by third parties, can assist in monitoring the quality of support. However, they are resource intensive, and not equally effective in all settings.

Overly formalised statutory approaches to quality assurance and oversight will be ineffective for informal supporters. Education, capacity building and incentives are more appropriate in such contexts. Informal monitoring can be achieved when there is more than one supporter, and 'multiple eyes' are there to look out for a person. Suspected abuse by supporters can be dealt through existing processes such as those facilitated by offices of the Public Guardian or Public Advocates. Where unpaid supporters carry some formal standing, their duties can be legislated, and tools like supported decision-making agreements can also give clearer expectations.

Recommendations 7.1 – 7.4 are designed to further this element:

7.1 Existing disability rights advocacy organisations and decision support infrastructure – such as offices of Public Advocates, Public Guardians and tribunals – should be appropriately funded and used to deliver education, guidance and oversight of supported decision-making practice.

7.2 Different approaches to safeguarding and monitoring are required for the various different types of supporters.

7.3 Education, training and financial incentives – rather than external regulatory monitoring, 'codes of conduct' or punitive measures – should be applied to improve the quality of supported decision-making by unpaid supporters.

7.4 For formal supporters a range of measures are needed such as service and professional codes of conduct, standards or accreditation about supported decision-making

Element 6: Enabling forward planning

Forward planning enables people to make arrangements for a future time when they might need additional decision support. Existing forward planning legal instruments are often associated with substitute decision-making; however, reforming and expanding these existing mechanisms has significant potential for realisation of a principled approach to supported decision-making. Legislative changes are needed to ensure instruments such as enduring powers of attorney comply with the principles of supported decision-making outlined above. Another challenge with forward planning is that will and preferences can change over time in a way that a person cannot always predict and plan for.

It certainly is true that forward planning for anticipation of cognitive decline through the use of enduring powers is now at least quite well understood by local solicitors consulted by families and members of the community. Healthcare and service providers also are quite familiar with those instruments, but principally due to their ‘convenience’ and their ‘risk protective’ appeal (as illustrated when service providers require such appointments as a precondition of entry to care). Even local solicitors and other members of the legal profession currently have little appreciation of a need to meaningfully engage with the will and preferences of the person for whom an enduring power is being prepared. Innovative measures need to be crafted to offer incentives for raising understanding in the professions, so there is greater receptivity to discussion of supported decision-making avenues with their clients.

Recommendations 8.1 – 8.5 are designed to further this element:

8.1 State and Territory laws should be reformed to offer the option for people to self-appoint a legally recognised supporter for decision-making (as in Victoria). However, consideration should be given to setting the lowest possible level of understanding needed for such appointments and to providing the option of appointing enduring supporters.

8.2 Create and widely disseminate ‘templates’ for forward planning that align with principles of supported decision-making and allow for recording statements of will and preferences.

8.3 Develop and deliver education programs – both for the public at large, and targeted at legal and medical professionals, disability and aged care support workforce – about the benefits and best practice for supported decision-making through forward planning.

8.4 Give particular attention to adapting forward planning legal instruments, templates and education for the needs of diverse people, by disability type and severity, and for people from diverse cultural backgrounds and First Nations people.

Element 7: Adequate funding

Little benefit and significant harm are likely from merely abolishing laws or programs that deny agency and autonomy, such as guardianship and other substitute decision-making, without providing adequate resources to supported decision-making. Adequate funding is needed to resource all elements of a supported decision-making framework, in particular, best practice, capacity building, oversight and monitoring and building social networks. Guardianship, unlike supported decision-making, is exclusively a ‘public’ program. Supported decision-making however is often informal, and as such involves additional costs for capacity-building. Relevant pilot programs were very small in scale but despite the advantage of recruiting the best of available strangers willing to provide support, the success rate in recruiting and retaining suitable supporters was low, and the organisational overheads were high (needing a close to full-time case manager to facilitate the process).

For people with no available family, friend or volunteer prepared and suitable to act, the cost per person being supported rises significantly. While paid dedicated decision supporters are an appropriate option of last resort for isolated people, funding should be kept separate from resourcing needed to promote the supported decision-making framework in general and it must not be permitted to lead to a new ‘industry’ delivering paid dedicated decision support.

Recommendations 9.1– 9.2 are designed to further this element:

9.1 A comprehensive cost-benefit analysis, accounting for the full cost of implementing a full package of supported decision-making programs, against an assessment of the benefits to society should be undertaken which should also map which levels and branches of government will bear which costs.

9.2 NDIS, aged care and other State or Territory schemes for individualised packages of funding for support for people with cognitive disabilities should fund supported decision-making for participants who have no access to informal sources of support.

Element 8: Building social connections

Many people with cognitive disability are socially isolated and have no access to a single informal supporter. For them, supported decision-making depends on the availability of paid supporters who are likely to be their primary service providers. Building social connections is therefore important to enable supported decision-making for people who are socially isolated. However, to date strategies for building social connections have tended to rely on a person already having a core supporter around whom a network could be generated.

Structured strategies such as microboards – primarily designed to enhance accountability and continuity in supported decision-making – are sometimes considered a mechanism for building people’s social networks. This advantage could potentially be obtained in more informal ways, short of setting up micro-boards, however there is a significant gap in evidence about costs and strategies for building and maintaining social connections for people with cognitive disabilities.

Recommendations 10.1 – 10.2 are designed to further this element:

10.1 A comprehensive research program to understand how to build social connections for people with cognitive disabilities who do not have existing strong family or informal relationships should be funded as a priority.

10.2 Demonstration programs to build lasting and robust social networks of people with cognitive disabilities who are socially isolated should be funded and evaluated as a priority.

10.3 Conclusions – Comprehensive, ambitious and measured policy, practice and law reform

Supported decision-making holds significant promise for furthering the rights of people with cognitive disabilities as members of our society and acting as a protective factor against abuse. The most relevant marker of supported decision-making is that an individual’s stated or perceived will and preferences remain the centre of any decision. Its raison d’etre is that every person with cognitive disability is known well and socially connected to supporters who recognise their right to express preferences about all aspects of life and for their preferences to be respected and acted upon. The Framework we propose recognises the current deep inequities of access to social connections and supported decision-making among people with cognitive disabilities and the recommended principled approach to supported decision-making includes all people with disabilities no matter how severe their cognitive impairment.

There remains considerable room to apply the principles and elements of the proposed framework to demonstration programs, experimental practice and innovative capacity building strategies as it is too early to settle on preferred models or arrangements for supported decision-making across the diverse groups and contexts where it must be implemented. Research and evaluation of innovations must continue to inform the development of programs and practices. Embedding supported decision-making within the diverse service and legal systems used by people with cognitive disabilities as well the informal and everyday aspects of their lives demands policy change and law reform. Fundamental however, to the success of reforms will be cultural change in our institutions, among professionals and throughout civil society so that supported decision-making becomes ‘what we do around here’.

As indicated throughout this Report, formulating and implementing a framework for supported decision-making is a major exercise in policy development. For supported decision-making to succeed, a framework and accompanying reform package must be comprehensive and holistic in character. It must be embedded in a cohesive and inclusive range of government, non-government agency and civil society measures. It should be ambitious; vigorously seeking to progress change across all parts of those programs, laws, systems and social processes. But in doing so it must adequately accommodate the often complex interactions, and unintended consequences encountered at the interfaces where supported decision-making engages the other, less compatible, elements where substitute decision-making is most prominent.

Sound public policy must be centred around co-leadership and co-design with people with cognitive disability and supporters of people with severe cognitive impairments, and engage all levels of government, non-government agencies, and civil society. The reform agenda needs to be both comprehensive and measured.

A comprehensive policy agenda would ensure that all Australians able to benefit from avoiding or delaying substitute decision-making have an opportunity to do so, while giving first priority to the most disadvantaged due to their social isolation, complexity and duration of need – such as those with lifelong disability and no one in their lives. It would avoid an undue focus on government at the expense of civil society, or on the national at the expense of other levels of government, or on legal reforms at the expense of social programs and consideration of the full array of public policy levers and incentives. A comprehensive reform agenda must reflect the scale and significance of impacts across several domains of disability type, service settings, intersectionality and manifold other features detailed in the proposed Framework.

A measured policy agenda for its part involves recognising that social reform is not effected merely by embracing new principles and objectives, adopting frameworks, or passing laws. A measured approach recognises the step-by-step process of obtaining meaningful progress over an adequate period of time in which to initiate, independently evaluate for effectiveness, and where necessary refine reform programs in light of evidence of their degree of success (or otherwise). A measured approach also entails recognition of the need for financial resourcing, cultural and institutional change, and public education. The Framework outlined in this Report has been designed to capture these features.

While legal changes will be an integral part of the reforms required by Australian systems, it is important to recognise that many aspects of the Framework can be implemented prior to, or alongside, legal reform. Our work has demonstrated that meaningful engagement with people with cognitive disabilities occurs through interactions with friends, families, associates or those within service systems that they navigate. Law reform plays only a small part in shifting societal, professional and institutional norms to one that views supported decision-making as the norm, rather than the exception.

Endnotes

1 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 15 (entered into force 3 May 2008)

2 J A Byrne, 'Improving the peer review of narrative literature reviews', (2016), vol 1(1), *Research Integrity and Peer Review*, pp 10–13; Megan Topping, Jacinta Douglas & Dianne Winkler, 'General considerations for conducting online qualitative research and practice implications for interviewing people with acquired brain Injury' (2021) vol 20 *International Journal of Qualitative Methods* 16094069211019615; Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, 'Supported Decision-making: The current state of knowledge', report prepared for the Royal Commission into Abuse, Violence, Neglect and Exploitation of People with Disability, February 2022; The issues canvassed included: if and how supported decision-making reduces the risk of violence, abuse, neglect and exploitation for people with disability in different contexts; what supported decision-making means and looks like in practice for people with disability; what past, existing and emerging supported decision-making programs and pilots have been developed in Australia and comparative jurisdictions; what underlying assumptions inform these approaches; what are the essential mechanisms of supported decision-making frameworks; how supported decision-making frameworks have been implemented for people with high support needs; how supported decision-making programs and pilots have been assessed or evaluated; what implementation issues have been identified for supported decision-making programs and pilots and whether these differed by disability or supporter groups or context; whether legislative action desirable as a basis for supported decision-making and what are the potential risks and impacts of a statutory supported decision-making framework on informal supported decision-making arrangements; what safeguards, monitoring and oversight mechanisms need to be in-place for a supported decision-making framework; and what are the gaps in research about supported decision-making.

3 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, 'Moving from support for decision-making to Substitute decision-making: legal frameworks and perspectives of Supporters of adults with intellectual disabilities', (2022), vol 37(3), *Law in Context* doi.org/10.26826/law-in-context.v37i3.174

4 Christine Bigby, Craig Sinclair, Julia Duffy, Ilan Wiesel, Terry Carney, Shih-Ning Then & Jacinta Douglas, *Perspectives of Supported Decision Making from Self Advocates, Supporters and Advocates*, July 2022.

5 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, 'Moving from support for decision-making to Substitute decision-making: legal frameworks and perspectives of Supporters of adults with intellectual disabilities', (2022), vol 37(3), *Law in Context* doi.org/10.26826/law-in-context.v37i3.174

6 *Guardianship and Administration Act 2019* (Vic)

7 Shih-Ning Then, Terry Carney, Christine Bigby & Jacinta Douglas, 'Supporting decision-making of adults with cognitive disabilities: the role of law reform agencies – recommendations, rationales and influence' (2018), vol 61(Nov/Dec) *International Journal of Law & Psychiatry*, pp 64—75; New South Wales Law Reform Commission, *Review of the Guardianship Act 1987*, May 2018 <http://www.lawreform.justice.nsw.gov.au/Documents/Current-projects/Guardianship/Report/Report%20145.pdf>; VLRC, 'Guardianship: Final Report', Victorian Law Reform Commission, 2012 <https://www.lawreform.vic.gov.au/publication/guardianship-report-pdf-2/>; TasLRInstitute, 'Review of the *Guardianship and Administration Act 1995* (Tas): Final Report', Tasmania Law Reform Institute, 2018 <https://www.utas.edu.au/__data/assets/pdf_file/0005/1178762/Guardianship-Final-Report.pdf>; ACT LRACL, 'Guardianship Report', ACT Law Reform Advisory Council, 2016 <https://www.justice.act.gov.au/publications-listing>

8 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, 'Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities', (2022), vol 37(3), *Law in Context* doi.org/10.26826/law-in-context.v37i3.174

9 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014); see discussion in: Anna Arstein-Kerslake, 'An empowering dependency: exploring support for the exercise of legal capacity', (2016), vol 18, *Scandinavian Journal of Disability Research,* pp 77—92.

10 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, 2014; Kristin Booth Glen, 'Introducing a new human right: Learning from others, bringing legal capacity home', (2018), vol 49(3), *Columbia Human Rights Law Review*, pp 1–96, 20.

11 Nina A Kohn, 'Realizing supported decision-making: what it does—and does not—require', (2021), vol 21(11), *The American Journal of Bioethics*, pp 313—56; Nina A Kohn, 'Legislating supported decision-making', (2021), vol 58(2), *Harvard Journal on Legislation*, pp 313—57.

12 Amanda Keeling, 'The problem of influence: autonomy, legal capacity and the risk of theoretical incoherence' in Mary Donnelly, Rosie Harding & Ezgi Tascioglu (ed), *Supporting Legal Capacity in Socio-Legal Context*, Hart, 2022, pp 39—56.

13 Joanne Watson, 'Assumptions of decision-making capacity: the role supporter attitudes play in the realisation of article 12 for people with severe or profound intellectual disability', (2016), vol 5(6), *Laws*, doi:10.3390/laws5010006; Joanne Watson, Hille Voss & Melissa J Bloomer, 'Placing the preferences of people with profound intellectual and multiple disabilities at the center of end-of-life decision making through storytelling', (2019), vol 44(4), *Research and Practice for Persons with Severe Disabilities*, pp 267—79; see also: Joanne Watson, Erin Wilson & Nick Hagiliassis, 'Supporting end of life decision making: case studies of relational closeness in supported decision making for people with severe or profound intellectual disability', (2017), vol 30(6), *Journal of Applied Research in Intellectual Disabilities*, pp 1022—34.

14 Bernadette Curryer, Roger J Stancliffe, Michele Y Wiese & Angela Dew, 'The experience of mothers supporting self-determination of adult sons and daughters with intellectual disability', (2020), vol 33(3), *Journal of Applied Research in Intellectual Disabilities*, pp 373—85; Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, 'Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities', (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174 Michelle Jennett Browning, 'Developing an understanding of supported decision-making practice in Canada: the experiences of people with intellectual disabilities and their supporter', PhD Thesis, La Trobe University, 2018, pp iii; Christine Bigby & Jacinta Douglas, 'Unpacking the complexities of the practice of support for decision-making' in Ishita Khemka & Linda Hickson (ed) *Decision-making by individuals with intellectual and developmental disabilities: research and practice*, Springer, 2021; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, 'Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences', (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.195448

15 Rosie Harding & Taşcıoğlu Ezgi,'Supported decision-making from theory to practice: Implementing the right to enjoy legal capacity', (2018), vol 8(2), *Societies (Basel, Switzerland)*, pp 25, doi:10.3390/soc8020025; Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, 'Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities' (2022) vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174; Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability',' (2020), *Social & Cultural Geography*, DOI: 10.1080/14649365.2020.1829689

16 See Principle 5.

17 See Principle 6.

18 In the case of adults with mental health conditions, concerns were expressed if Community Treatment Orders were not available due to the risk of harm: Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, 'Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners', (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826-33; Lisa Brophy, Renata Kokanovic, Jacinthe Flore, Bernadette McSherry & Helen Herrman, 'Community treatment orders and supported decision-making', (2019), vol 10, *Frontiers in Psychiatry*, 414:1–12; but also more generally Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, 'Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters

of adults with intellectual disabilities' (2022), vol 37(3), *Law in Context [Internet]* Available from: https://journals.latrobe.edu.au/index.php/law-in-context/article/view/174.

19 Terry Carney, Christine Bigby, Shih-Ning Then, Elizabeth Smith, Ilan Wiesel & Jacinta Douglas,, 'Paternalism to Empowerment: All in the eye of the beholder?' (2021), *Disability & Society* Ahead of print https://doi.org/10.1080/09687599.09682021.01941781; Lucy Knox, Jacinta Douglas & Christine Bigby, '"I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents', (2016) *Neuropsychological Rehabilitation,* pp 236–260; Jane Tracy, 'Supporting Nick to make decisions: an exploration of ways to promote choice and control', (2015), vol 2(1), *Research and practice in intellectual and developmental disabilities*, pp 29–36.

20 These include for instance restrictive practices in the form of chemical restraint, seclusion, environmental restraint, mechanical restraint, and physical restraint. Restrictive practices is the subject of a separate research contracted by the Commission: Claire Spivakovsky, Linda Steele, Dinesh Wadiwel, *Restrictive Practices: A Pathway to Elimination*, Report being prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (forthcoming).

21 Christine Bigby, Jacinta Douglas and Lisa Hamilton, *Overview of Literature About Enabling Risk for People with Cognitive Disabilities in Context of Disability Support Services*, Living with Disability Research Centre, La Trobe University, 2018.

22 Robert Perske, 'The dignity of risk', in W Wolfensberger et al (ed), *The principle of normalization in human services,* National Institute of Mental Retardation, 1972, pp194-200; see also Piers Gooding, 'Supported Decision-Making: A Rights-Based Disability Concept and Its Implications for Mental Health Law' (2013) vol 20(3) *Psychiatry, Psychology and Law*, pp 431–451.

23 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, ALRC Report 124, 2014, p 53.

24 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report,* ALRC Report 124, 2014.

25 New South Wales Law Reform Commission, **'***Review of the Guardianship Act 1987*', May 2018.

26 Christine Bigby, Jacinta Douglas, Suzanne Vassallo & Lisa Hamilton, 'Enabling Risk: Putting Positives First– On line training program', 2018 https://www.enablingriskresource.com.au; Christine Bigby, Jacinta Douglas& Lisa Hamilton, *Overview of literature about enabling risks for people with intellectual disabilities on the context of disability support services*, Report for NSW Family and Community Services, Living with Disability Research Centre, La Trobe University, 2018; Department of Health, United Kingdom, *Nothing ventured, nothing gained: risk guidance for people with dementia.*, 2010.

27 *Mental Health Act 2016* (Qld) s 13 includes advance health directives as a 'less restrictive way'.

28 Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel, Jacinta Douglas & Elizabeth Smith, 'Realising 'Will, preferences and rights': reconciling differences on best practice support for decision-making?' (2019) vol 28(4) *Griffith Law Review*, pp 357–79; see also Patrick McKearney, 'Challenging care: Professionally not knowing what good care is', (2020), vol 45(2), *Anthropology and Humanism*, pp 223–32.

29 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social &Cultural Geography* DOI: 10.1080/14649365.2020.1829689

30 While the focus of this exception is on risk of harm to the person, we recognise that the risk of incurring civil or criminal liability means that some harms to others are also appropriately captured.

31 The threshold for when this exception can be used excludes risk of 'emotional' harm. This exception should be understood as a narrow exception; the danger with including 'emotional' harm is that it can be interpreted in many different ways by different people and could be used to inappropriately widen the scope of this exception.

32 See for example: Ranjana Srivastava, 'Doctor, can I drink water?' – why the simplest of questions can be the most upsetting', *The Guardian (Australian ed)*, 27 April 2022.

33 *Guardianship and Administration Act 2019* (Vic).

34 See Principle 7.

35 Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, ‘Supported decision-making: the current state of knowledge, report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability’, February 2022, pp 52–56.

36 Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, ‘Supported decision-making: the current state of knowledge, report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability’, February 2022, pp 52–56.

37 Lucy Knox, Jacinta Douglas & Christine Bigby, ‘”I’ve never been a yes person”: decision-making participation and self-conceptualization after severe traumatic brain injury’, (2017), vol 39(22), *Disability and Rehabilitation*, pp 2250–60.

38 Deirdre Fetherstonhaugh, Laura Tarzia & Rhonda Nay, ‘Being central to decision-making means I am still here!: The essence of decision-making for people with dementia’, (2012), vol 27(2), *Journal of Aging Studies*, pp 143–50.

39 Sarah E Keyes, Charlotte L Clarke & Catherine E Gibb, ‘Living with dementia, interdependence and citizenship: narratives of everyday decision-making’, (2019), vol 34(2), *Disability & Society*, pp 296–319, 106–7.

40 Sophie Nunnelley, *Personal support networks in practice and theory: assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015 pp 36, 98–99; Kevin De Sabbata & Elena Syurina, *Supported decision-making and dementia*, Psychiatrie Verlag, 2019, p 25; Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A real bucket of worms”: Views of people living with dementia and family members on supported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587–608; Kevin De Sabbata, ‘Dementia, treatment decisions, and the UN Convention on the Rights of Persons With Disabilities: a new framework for old problems’, (2020), vol 11, *Frontiers in Psychiatry*, doi: 10.3389/fpsyt.2020.571722

41 Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, ‘Supported Decision-making: The current state of knowledge’, report prepared for the Royal Commission into Abuse, Violence, Neglect and Exploitation of People with Disability, February 2022.

42 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘“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’, (2021), *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences’, (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481

43 Christine Bigby, Mary Whiteside & Jacinta Douglas, *Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas*, Living with Disability Research Centre, La Trobe University, 2015; Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.

44 Shirli Werner & Rachel Chabany, ‘Guardianship law versus supported decision-making policies: Perceptions of persons with intellectual or psychiatric disabilities and parents’, (2016), vol 86(5), *American Journal of Orthopsychiatry*, pp 486–99, 493

45 Lalcheva, Radoslava & Miryana Malamin, *Cost Benefit Analysis of Supported Decision-Making*, 2014.

46 See eg Bruce Alston, ‘Towards supported decision-making: article 12 of the Convention on the Rights of persons with Disabilities and guardianship law reform’, (2017), vol 35(2), *Law in Context*, pp 21–39; Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third reports of Australia (Advance Unedited Version)*, UN Doc CRPD/C/AUS/CO/2–3.

47 Principle 1.

48 Principle 2.

49 Principle 3.

50 Principle 4.

51 Principle 5.

52 Principle 6.

53 Principle 7.

54 Terry Carney, ‘Prioritising supported decision-making: running on empty or a basis for glacial-to-steady progress?’ (2017), vol 6(18), *Laws* pp 1–14.

55 See for example in pilots where people without supporters were identified and endeavours made to find supporters: Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, ‘Supported Decision-making: The current state of knowledge’, report prepared for the Royal Commission into Abuse, Violence, Neglect and Exploitation of People with Disability, February 2022, Tables 1.1, 1.2, 2.1, 2.2

56 OPA/VALiD, ‘Volunteer Programs of Support for Decision-making: Lessons and recommendations from the OVAL project’, Office of Public Advocate Victoria, 2017.<https://www.publicadvocate.vic.gov.au/opa-s-work/research/144-research-item-on-frontpage>: 23.

57 Roni Holler & Shirli Werner, ‘”Necessity is neither condemned nor praised”: social workers’ meanings of guardianship for disabled people’ (2022), vol 52, *British Journal of Social Work,* pp 98–115

58 See Principle 8.

59 G Goetz Ottmann, Keith McVilly & Margarita Maragoudaki, ‘’I walk from trouble’: exploring safeguards with adults with intellectual disabilities – an Australian qualitative study’, (2016), vol 31(1), *Disability & Society*, pp 47–63, 60.

60 See Principle 9.

61 M McCarron, P McCallion, E Reilly & N Mulryan, ‘A prospective 14-year longitudinal follow-up of dementia in persons with Down syndrome: Dementia follow-up’, (2014), vol 58 (1), *Journal of Intellectual Disability Research*, pp 61–70; Terry Carney & Shih-Ning Then, ‘Support for decision-making as people age with a cognitive impairment’ in Michelle Putnam & Christine Bigby (ed) *Handbook on Ageing with Disability*, Routledge, 2021, pp 186–95.

62 Tim Stainton, ‘Supported decision-making in Canada: principles, policy, and practice’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 1–11; Michelle Browning, Christine Bigby & Jacinta Douglas, ‘A process of decision-making support: exploring supported decision-making practice in Canada’, (2021), vol 46(2), *Journal of Intellectual & Developmental Disability*, pp 138–49.

63 Ben Colburn, *Autonomy and Liberalism*, Taylor & Francis, 2010; Jonas Sébastien-Beaudry, *The disabled contract: severe intellectual disability, justice and morality,* Cambridge University Press, 2021.

64 Anita Gjermestad, Laila Luteberget, Turid Midjo & Aud Elisabeth Witsø, ‘Everyday life of persons with intellectual disability living in residential settings: a systematic review of qualitative studies’, (2017), vol 32(2), *Disability & Society*, pp 213–32.

65 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context [Internet]* Available from: https://journals.latrobe.edu.au/index.php/law-in-context/article/view/174

66 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context [Internet]* Available from: https://journals.latrobe.edu.au/index.php/law-in-context/article/view/174

67 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences’ (2021) *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.195448; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘“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', (2021), *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, 'Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences', (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481; Jacinta Douglas & Christine Bigby (under review). The Decision Support *Questionnaire*: Development, reliability and validity. *Disability and Rehabilitation*

68 Lucy Knox, Jacinta Douglas & Christine Bigby, ''The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI', (2015), vol 29(6), *Brain Injury*, pp 745–57, 745.

69 Lucy Knox, Jacinta Douglas & Christine Bigby, ''The biggest thing is trying to live for two people': spousal experiences of supporting decision-making participation for partners with TBI', (2015), vol 29(6), *Brain Injury*, pp 745–57.

70 Australian Institute of Health and Welfare, 'Disability in Australia: acquired brain injury, December 2007, vol 55 *Bulletin,* 1.

71 Jacinta Douglas, 'The things that help, the things that get in the way: working together to improve outcome following acquired brain injury, presidential address', (2018), vol 19(3), *Brain Impairment,* pp 258-269, 258.

72 Jacinta Douglas, 'Conceptualising self and maintaining social connection following severe traumatic brain injury', (2013), vol 27(1), *Brain Injury,* pp 60–74. https://doi-org.ez.library.latrobe.edu.au/10.3109/02699052.2012.722254 W Levack, M Kayes & J Fadyl, 'Experience of recovery and outcome following traumatic brain injury: A metasynthesis of qualitative research', (2010), vol 32, *Disability and Rehabilitation*, pp 986–999;H Muenchberger, E Kendall & R Neal, 'Identity transition following traumatic brain injury: a dynamic process of contraction, expansion and tentative balance' (2008), vol 22, *Brain Injury,* pp 979–992.

73 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social &Cultural Geography*, p 11 DOI: 10.1080/14649365.2020.1829689

74 Lucy Knox, Jacinta Douglas & Christine Bigby, "I won't be around forever": understanding the decision-making experiences of adults with severe TBI and their parents', (2016) vol 26 (2) *Neuropsychological Rehabilitation,* pp 236–260; Lucy Knox, Jacinta Douglas & Christine Bigby, 'Becoming a decision-making supporter for someone with acquired cognitive disability following TBI' (2016), vol 3 (1) *Research and Practice in Intellectual and Developmental Disabilities*, pp 12–21. DOI: 10.1080/23297018.2015.1077341; Jacinta Douglas, Christine Bigby, Lucy Knox & Michelle Browning, 'Factors that Underpin the Delivery of Effective Decision-Making Support for People with Cognitive Disability', (2015), vol 2(1), *Research and Practice in Intellectual and Developmental Disabilities* pp 37–44.

75 Jacinta Douglas, Christine Bigby & Elizabeth Smith, *Building capability to support client decision-making: TAC Project No. T005*, Living with Disability Research Centre, La Trobe University, 2020.

76 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587–608, 601.

77 Terry Carney & Shih-Ning Then, 'Support for decision-making as people age with a cognitive impairment' in (ed) Michelle Putnam & Christine Bigby *Handbook on Ageing with Disability*, Routledge, 2021, pp 186–95.

78 See for example *Medical Treatment Planning and Decisions Act 2016* (Vic) Part 3; *Powers of Attorney Act 1998* (Qld) ss32, 33, 35(1)(c), 36 (3)–(5); *Powers of Attorney Act 2006* (ACT) s 13; *Guardianship Act* (NSW) s 6E; *Advance Personal Planning Act* (NT) s 16, *Advance Care Directives Act* 2013 (SA) s 21, 23; *Guardianship and Administration Act 1995* (Tas) s 32, *Guardianship and Administration Act 1990* (WA) s 110G

79 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": views of

people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587–608, 595.

80 Mary Donnelly, 'Deciding in dementia: the possibilities and limits of supported decision-making', (2019), vol 66, *International Journal of Law and Psychiatry*, 101466: 1-7; Laura Pritchard-Jones, 'Exploring the potential and the pitfalls of the United Nations Convention on the Rights of Persons with Disabilities and General Comment No. 1 for people with dementia', (2019), vol 66, *International Journal of Law and Psychiatry*, 101467: 1–7; Amanda Keeling, 'Supported decision-making: the rights of people with dementia'', (2016), vol 30(30), *Nursing Standard*, pp 38–44.

81 Megan Wright, 'Dementia, cognitive transformation, and supported decision-making', (2020), vol 20(8), *American journal of bioethics*, pp 88–90, 88; Terry Carney, 'Combating elder abuse: any role for supported-decision-making, adult guardianship or other laws?' in (ed) Mala Kapur Shankardass *Combating Elder Abuse in Australia and India*, Nova Science, 2020, pp 265–87; Anita Smith & Danny Sullivan, 'A new ball game: the United Nations Convention on the Rights of Persons with Disabilities and assumptions in care for people with dementia', (2012), vol 20(1), *Journal of Law and Medicine*, pp 28–34.

82 T Haeusermann, 'Forced continuity: Explorations of biographical narratives in dementia care', (2019), vol 49, *Journal of Aging Studies,* pp1–8. doi:https://doi.org/10.1016/j.jaging.2019.02.001

83 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587–608.

84 https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/

85 Theresa S Wied, Aoife Poth, Johannes Pantel, Frank Oswald & Julia Haberstroh, 'How do dementia researchers view support tools for informed consent procedures of persons with dementia?', (2020), *Zeitschrift Fur Gerontologie Und Geriatrie*, https://doi.org/10.1007/s00391-020-01779-2; Theresa Wied, Matthe Scholten, Julia Haberstroh and Johanne Pantel, 'Supported decision-making in persons with dementia: development of an enhanced consent procedure for lumbar puncture,https://www.researchgate.net/profile/Matthe-Scholten/publication/356266883 Julia Lühnen, Burkhard Haastert, Ingrid Mühlhauser & Tanja Richter, 'Informed decision-making with and for people with dementia - efficacy of the PRODECIDE education program for legal representatives: protocol of a randomized controlled trial (PRODECIDE-RCT)', (2017), vol 17(1), *BMC Geriatrics*, 217: 1–11.

86 Paul Skowron, 'Giving substance to 'the best interpretation of will and preferences'', (2019), vol 62, *International Journal of Law and Psychiatry*, pp 125-34; George Szmukler, ''Capacity', 'best interests', 'will and preferences' and the UN Convention on the Rights of Persons with Disabilities', (2019), vol 18(1), *World Psychiatry*, pp 34-41; Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel, Jacinta Douglas & Elizabeth Smith, 'Realising 'Will, preferences and rights': reconciling differences on best practice support for decision making?' (2019,) vol 28(4), *Griffith Law Review*, pp 357-79.

87 For example, In Australia: *Mental Health Act 2016* (Qld), *Mental Health Act 2014* (Vic), *Mental Health Act 2007* (NSW), *Mental Health Act 1996 (*WA), *Mental Health and Related Services Act* (NT)

88 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014) [7].

89 Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melborune, 2017.

90 Fauzia Knight, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, Kate Johnston-Ataata & Helen Herrman, 'Supported decision-making: the expectations held by people with experience of mental illness', (2018), vol 28(6), *Qualitative Health Research*, pp 1002–15.

91 Lisa Brophy, Renata Kokanovic, Jacinthe Flore, Bernadette McSherry & Helen Herrman, 'Community treatment orders and supported decision-making', (2019), vol 10, *Frontiers in Psychiatry*, 414:1–12; Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Nicholas Hill, Kate

Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Social Equity Institute, University of Melbourne, 2017, pp 40-41; Meredith Stone, Renata Kokanovic, Felicity Callard & Alex F Broom, ‘Estranged relations: coercion and care in narratives of supported decision-making in mental healthcare’, (2020), vol 46(1), *Medical Humanities*, pp 62–72

92 Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, ‘Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners’, (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826–33.

93 Kanna Sugiura, Faraaz Mahomed, Shekhar Saxena & Vikram Patel, ‘An end to coercion: rights and decision-making in mental health care’, (2020), vol 98 (1), *Bulletin of the World Health Organization*, pp 52–8; Faraaz Mahomed, Michale Ashley Stein, Vikram Patel & Charlene Sunkel, ‘Introduction – a “Paradigm Shift” in mental health care’ in (ed) Faraaz Mahomed, Michale Ashley Stein, Vikram Patel & Charlene Sunkel *Mental Health, legal capacity and human rights*, Cambridge University Press, 2021, pp 1–16.

94 Joel D Corcoran, Cindy Hamersma & Steven Manning, ‘The Clubhouse Model: A framework for naturally occurring supported decision-making’ in (ed) Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel, *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 260–72.

95 Kanna Sugiura, Faraaz Mahomed, Shekhar Saxena & Vikram Patel, ‘An end to coercion: rights and decision-making in mental health care’, (2020), vol 98(1), *Bulletin of the World Health Organization*, pp 52–58.

96 Fiona Morrissey, ‘The United Nations Convention on the Rights of Persons with Disabilities: a new approach to decision-making in mental health law’, (2012), vol 19(5), *European Journal of Health Law*, pp 423–40; Piers Gooding, ‘Supported decision-making: a rights-based disability concept and its implications for mental health law’, (2013), vol 20(3), *Psychiatry, Psychology and Law*, pp 431–51; Fiona Morrissey, ‘The United Nations Convention on the Rights of Persons with Disabilities: a new approach to decision-making in mental health law’, (2012), vol 19(5), *European Journal of Health Law*, pp 423–40; M Cleary, T Raeburn, P Escott, S West & V Lopez, ‘”Walking the tightrope’: The role of peer support workers in facilitating consumers’ participation in decision-making’, (2018), vol 27(4), *International Journal of Mental Health Nursing*, pp 1266–72

97 Piers Gooding, ‘Supported decision-making: A rights-based disability concept and its implications for mental health law’, (2013), vol 20(3), *Psychiatry, Psychology and Law*, pp 431–51, 444.

98 Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas,, ‘Supported Decision-making: The current state of knowledge’, report prepared for the Royal Commission into Abuse, Violence, Neglect and Exploitation of People with Disability, February 2022.

99 S Avery, *“Something Stronger”: Truth-telling on hurt and loss, strength and healing, from First Nations people with disability,* Royal Commission on the Violence, Abuse, Neglect, and Exploitation of People with Disability. Sydney, Australia, 2020.

100 Jayne Clapton, Lesley Chenoweth, Natalie Clements, Vicki Pascoe, Kylie Radal, Yvonne Cadet James, Val Wallace & Diane Cadet-James, Impaired Decision-Making Capacity and Indigenous Queenslanders: Final Report for the Office of the Public Advocate, Queensland, (State of Qld, Department of Justice and Attorney-General, 2011), p 9; Julian Laurens, Shona Bates, Rosemary Kayess & Karen Fisher, Good practice in supported decision-making for people with disability: final report, Social Policy Research Centre (UNSW), 15 June 2021.

101 Shouli Shahid et al, ‘Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: a comprehensive review’, (2018,) vol 17(1) *BMC Palliative Care*, 72: 1–20.

102 Karen Soldatic, Georgia van Toorn, Leanneand Dowse & Kirsty Muir, ‘Intellectual Disability and complex intersections: Marginalisation under the National Disability Insurance Scheme’, (2014), vol 1(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 6-16, 11; see also: Eileen Baldry, Ruth McCausland, Leanne Dowse & Elizabeth McEntyre, *A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system*, University of New South Wales, 2015.

103 Eileen Baldry, Ruth McCausland, Leanne Dowse & Elizabeth McEntyre, *A predictable and preventable path: aboriginal people with mental and cognitive disabilities in the criminal justice system*, University of New South Wales, 2015, pp 13.

104 Office of the Public Advocate (Vic), *Walk with me, talk with me: A practice guide for OPA staff*, (2018).

105 Julian Laurens, Shona Bates, Rosemary Kayess & Karen Fisher, *Good practice in supported decision-making for people with disability: final report*, Social Policy Research Centre (UNSW), 15 June 2021, pp 13–15, 21–22.

106 Julian Laurens, Shona Bates, Rosemary Kayess & Karen Fisher, *Good practice in supported decision-making for people with disability: final report*, Social Policy Research Centre (UNSW), 15 June 2021, 21.

107 Julian Laurens, Shona Bates, Rosemary Kayess & Karen Fisher, *Good practice in supported decision-making for people with disability: final report*, Social Policy Research Centre (UNSW), 15 June 2021, 79.

108 New South Wales Law Reform Commission, *Review of the Guardianship Act 1987*, Report 145, May 2018, 36.

109 Julian Laurens, Shona Bates, Rosemary Kayess & Karen Fisher, *Good practice in supported decision-making for people with disability: final report*, Social Policy Research Centre (UNSW), 15 June 2021, pp xlii, xlvi

110 Cheryl Tilse, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, 'Managing older people's money: assisted and substitute decision-making in residential aged-care', (2011), vol 31(1), *Ageing & Society*, pp 93–109.

111 Lana Zannettino, Dale Bagshaw, Sarah Wendt & Valerie Adams, 'The role of emotional vulnerability and abuse in the financial exploitation of older people from culturally and linguistically diverse communities in Australia', (2015), vol 27(1), *Journal of Elder Abuse & Neglect*, pp 74–89.

112 Lana Zannettino, Dale Bagshaw, Sarah Wendt & Valerie Adams, 'The role of emotional vulnerability and abuse in the financial exploitation of older people from culturally and linguistically diverse communities in Australia', (2015), vol 27(1), *Journal of Elder Abuse & Neglect*, pp 74–89, 74.

113 Canadian Centre for Elder Law, *Study Paper on Inclusive Investing: Respecting the Rights of Vulnerable Investors through Supported Decision-Making*, 2021, p 198.

114 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": Views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587–608, 598.

115 Craig Sinclair, Susan Kurrle, Sue Field, Meera Agar, Kathy Williams, Romola Bucks, Josephine Clayton, Cameron Stewart, Meredith Blake, Kirsten Auret, Meredith Gresham, Angelilta Martini & Helen Radoslovich, *Supported Decision-Making in Dementia Care: Final Project Report*, NHMRC Cognitive Decline Partnership Centre, 2019, p 28.

116 Sandra B Vanegas, Sandy Magaña, Weiwen Zeng & Carlos Pavon 'Decision-making and culturally diverse individuals with IDD and their families: A call for research' in Ishita Khemka & Linda Hickson (ed) *Decision-making by Individuals with Intellectual and Developmental Disabilities: Integrating Research into Practice*, Springer International Publishing, 2021, pp 221–51.

117 Nancy J Knauer, 'LGBT issues and adult guardianship: a comparative perspective' in Kim Dayton (ed) *Comparative perspectives in guardianship*, University of Carolina Press, 2013.

118 Nathan J Wilson, Jemima Macdonald, Brenda Hayman, Alexandra M Bright, Patsie Frawey & Gallego. Gisselle, 'A narrative review of the literature about people with intellectual disability who identify as lesbian, gay, bisexual, transender, intersex or questioning', (2018), vol 22 (2), *Journal of Intellectual Disabilities*, pp 79-96; Elizabeth Smith, Tessa-May Zirnsak, Jennifer Power, Anthony Lyons & Christine Bigby, 'Social inclusion of LGBTQ and gender diverse adults with intellectual disability in disability services: a systematic review of the literature', (2021), *Journal of applied research in intellectual disabilities*, DOI: 10.1111/jar.12925.

119 See for example the Network's 2016 Discussion paper calling for a national framework: https://www.aph.gov.au/DocumentStore.ashx?id=d11cd090-edf2-4a4e-b1b6-3d4c601f15e7&subId=512644

120 We note the high proportion of people with cognitive disabilities who interact with the criminal justice system: Leanne Dowse, Simon Rowe, Eileen Baldry & Michael Baker, *Police responses to people with disability: Research Report prepared for the Disability Royal Commission,* October 2021 See also: 'The majority of people with disability who come into contact with criminal justice systems have some form of cognitive disability, including intellectual disability; acquired brain injury (including those related to traumatic brain injury e.g., assaults, motor vehicle accidents; and those related to a non-traumatic brain injury e.g., substance abuse, stroke, illness), autism spectrum disorders and fetal alcohol spectrum disorders.' https://disability.royalcommission.gov.au/system/files/2021-10/Research%20Report%20-%20Police%20responses%20to%20people%20with%20disability.pdf

121 Silja Häusermann, 'Welfare state research and comparative political economy' (2018) *Oxford Research Encyclopedia of Politics* https://doi.org/10.1093/acrefore/9780190228637.9780190228013.9780190228654; Ellen Minkman, MW Van Buuren and VJJM Bekkers, 'Policy transfer routes: an evidence-based conceptual model to explain policy adoption' (2018) vol 39(2) *Policy Studies*, pp 222-250; Tim Legrand, *The Architecture of Policy Transfer,* Palgrave Macmillan, 2021.

122 Daniel Bertram, 'Accounting for culture in policy transfer: a blueprint for research and practice' (2020) *Political Studies Review* ahead of print https://doi.org/10.1177/1478929920965352

123 Nina A Kohn, 'Legislating supported decision-making' (2021) vol 58 *Harvard Journal on Legislation* pp 313–356.

124 Ulrika Järkestig Berggren, 'The Swedish Personal Ombudsman: support in decision-making and accessing human rights' in Michael Ashely Stein, Faraaz Mahomed, Vikram Patel, Charlene Sunkel & Juliana Lynn Restivo (ed), *Mental Health, Legal Capacity, and Human Rights*, Cambridge University Press, 2021, pp 230–243.

125 Government of Alberta, *Legislative Review of the Dependent Adults Act and the Personal Directives Act: Final Report and Recommendations*, Government of Alberta, Legislative Review (Ms Cindy Ady, chair), January 2007 <http://www.seniors.gov.ab.ca/services_resources/opg/leg_review/FinalReport.pdf>

126 *Capacity of Adults with Mental Disabilities and the Federal RDSP*, Law Commission of Ontario, 2013 <http://www.lco-cdo.org/rdsp-discussion-paper.pdf>; 'Capacity and Legal Representation for the Federal RDSP—Final Report', Law Commission of Ontario, 2014 <http://www.lco-cdo.org/en/rdsp-final-report>

127 L Phillipson, L F Low, & S Dreyfus, 'Consumer-directed care for older Australians: are resources identified on the Web adequate to support decisions about home-based care packages?', (2019), vol 54(2), *Australian Journal of Social Issues,* pp 135–156.

128 See: *Guardianship and Administration Act 2000* (Qld) s66; *Medical Treatment Planning and Decisions Act 2016* (Vic) s 55; *Guardianship and Administration Act 1990* (WA) s 110ZJ; s *Guardianship Act 1997* (NSW) 33A; Ben White, Lindy Willmott and Shih-Ning Then, 'Adults who lack capacity: substitute decision-making' in Ben White, Fiona McDonald & Lindy Willmott (ed), *Health Law in Australia*, Thompson Reuters Lawbook Co, 3rd ed, 2021, pp 207–270; also, https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws

129 *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 14(1) (definition of "person responsible"); *Powers of Attorney Act 1998* (Qld) ss 62, 63; s *Guardianship Act 1997* (NSW) ;Lindy Willmott et al, 'Guardianship and health decisions in China and Australia: a comparative analysis', (2017), vol 12(2), *Asian Journal of Comparative Law*, pp 371–400; Ben White, Lindy Willmott & Shih-Ning Then, 'Adults who lack capacity: substitute decision-making' in Ben White, Fiona McDonald & Lindy Willmott (eds), *Health Law in Australia*, Thompson Reuters Lawbook Co, 3rd ed, 2018, pp 207–270.

130 Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton, Helen Radoslovich, Meera Gar & Susan Kurrle, 'Professionals' views and experiences in supporting decision-making involvement for people living with dementia', (2021), vol 20(1) *Dementia* 84–105.

131 Jill Stavert, 'Paradigm shift or paradigm paralysis? National mental health and capacity law and implementing the CRPD in Scotland', (2018), vol 7(3), *Laws*, pp 26–41.

132 Giles Newton-Howes & Sarah Gordon, 'Who controls your future: the Convention on the Rights of Persons with Disabilities from a service user focused perspective', (2020), vol 54(2), *Australian and New Zealand Journal of Psychiatry*, pp 134–7; James Cooney, Michael Daly, Giles Newton-Howes, Kris Gledhill & Sarah Gordon, 'Making the Convention on the Rights of Persons with Disabilities real: our word is our bond', (2021), vol 134(1534), *The New Zealand Medical Journal (Online)*, pp 8–10; Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, 'Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners', (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826–33.

133 Eg *Guardianship and Administration Act 2000* (Qld) s 11B.

134 Carmel Davies, Francesco Fattori, O'Donnell Deirdre, Sarah Donnelly, Shé Éidín Ní, Marie O Shea, Lucia Prihodova, Caoimhe Gleeson, Áine Flynn, Bernadette Rock, Jacqueline Grogan, O'Brien Michelle, O'Hanlon Shane, Marie Therese Cooney, Marie Tighe & Thilo Kroll, 'What are the mechanisms that support healthcare professionals to adopt assisted decision-making practice? A rapid realist review', (2019), vol 19, *BMC Health Services Research*, pp 1–14, 8; see also Kevin De Sabbata & Elena Syurina, *Supported decision-making and dementia*, Psychiatrie Verlag, 2019; Sarah Donnelly et al, Assisted decision-making and interprofessional collaboration in the care of older people: A qualitative study exploring perceptions of barriers and facilitators in the acute hospital setting' (2021) *Journal of interprofessional Care,* pp 1–1; Megan Wright, 'Implementing ethical and legal supported decision-making: some unresolved issues', (2021), vol 21(11), *The American Journal of Bioethics*, pp 40–42.

135 See for example: Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, 2017; Paul S Appelbaum & Manuel Trachsel, 'The doctrine of informed consent doesn't need modification for supported decision-making', (2021), vol 2(11), *The American Journal of Bioethics*, pp 27-29

136 Magenta Simmons & Piers Gooding, 'Spot the difference: shared decision-making and supported decision-making in mental health', (2017), vol 34 (4), *Irish Journal of Psychological Medicine*, pp 275–86; note also in the mental health context shared decision-making encouraged by the Supported decision-making Centre approach developed by Midwestern US cited in Susan Campbell, Karen Stowe & Elissa M Ozanne, 'Interprofessional practice and decision support: an organizational framework applied to a mental health setting', (2011), vol 25(6), *Journal of Interprofessional Care*, pp 423–7. In the dementia context shared decision-making is widely recognised and considered to be beneficial, with decision aids such as pamphlets, books, videos etc found to be useful in providing relevant and structured information John Carmody, Victoria Traynor & Anna Steele, 'Dementia, decision aids and general practice', (2015), vol 44(5), *Australian Family Physician*, pp 307–10; Kari Lislerud Smebye, Marit Kirkevold & Knut Engedal, 'How do persons with dementia participate in decision-making related to health and daily care? A multi-case study', (2012), vol 12(1), *BMC health services research*, pp 241–241; Rachel Louise Daly, Frances Bunn & Claire Goodman, 'Shared decision-making for people living with dementia in extended care settings: a systematic review', (2018), vol 8(6), *BMJ Open* e018977-e018977; more generally see Carmelle Peisah, Oluwatoyin A. Sorinmade, Leander Mitchell & Cees M. P. M. Hertogh, 'Decisional capacity: toward an inclusionary approach', (2013), vol 25(10), *International Psychogeriatrics*, pp 1571–79; Lyndsey M Miller, Carol J Whitlatch & Karen S Lyons, 'Shared decision-making in dementia: a review of patient and family carer involvement', (2016), vol 15(5), *Dementia*, pp 1141–57.

137 Glyn Elwyn, Dominick Frosch, Richard Thomson, Natalie Joseph-Williams, Amy Lloyd, Paul Kinnersley, Emma Cording, Dave Tomson, Carole Dodd, Stephen Rollnick, Adrian Edwards & Michael Barry, 'Shared decision-making: a model for clinical practice', (2012), vol 27(10), *Journal of General Internal Medicine: JGIM*, pp 1361–67.

138 Devora Shapiro, Lauren R Sankary & Paul J Ford, 'Reconciling supported decision-making with shared decision-making in the context of potential vulnerability', (2021), vol 21(11), *The American Journal of Bioethics*.; Karen Strickland, Kasia Bail, Sarah Cope, Murray Turner & Cameron Moss, 'Supported decision-making to assist older persons experiencing elder abuse: an integrative

review', (2021), vol 28(4), *Collegian*, pp 447–55; Kevin T Mintz & David C. Magnus, 'Disability, aging, and the importance of recognizing social supports in medical decision-making', (2021), vol 21(11), *The American Journal of Bioethics*, pp 1–3.

139 Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Insitute, University of Melbourne, 2017; Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, 'Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners', (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826-33; Sarah Donnelly et al, 'Assisted decision-making and interprofessional collaboration in the care of older people: A qualitative study exploring perceptions of barriers and facilitators in the acute hospital setting' (2021) *Journal of interprofessional Care,* pp 1–11.

140 Deirdre O'Donnell, Éidín Ní Shé, Carmel Davies, Sarah Donnelly, Therese Cooney, Diarmuid O'Coimin, Diarmuid O'Shea, Lorraine Kyne, Diarmaid O'Sullivan, Bernadette Rock, Marie O'Shea, Eilish McAuliffe, Ann O'Shaughnessy & Thilo Kroll, 'Promoting assisted decision-making in acute care settings for care planning purposes: study protocol', (2018), vol 1, *HRB Open Research*, 2 https://doi.org/10.12688/hrbopenres.12797.1

141 Australian Institute of Health and Welfare, *Dementia in Australia: Web Report (Last updated 20 Sep 2021)* 2021; Quality and Safety Royal Commission into Aged Care, *Dementia in Australia: Nature, Prevalence and Care: Background Paper 3*, 2019.

142 G E Caughey, C E Lang, S C Bray, M Moldovan, R N Jorissen, S Wesselingh & M C Inacio, International and National Quality and Safety Indicators for Aged Care: Report for the Royal Commission into Aged Care Quality and Safety, 2020.

143 Cheryl Tilse, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, 'Managing older people's money: assisted and substitute decision-making in residential aged-care', (2011), vol 31(1), *Ageing & Society*, pp 93–109.

144 Bethany Brown, '"For your own good:" Choice and the dangers of institutionalisation for older people', (2018), vol 27(1), *Human Rights Defender*, pp 12–14; Craig Sinclair, Sue Field, Meredith Blake & Helen Radoslovich, 'An examination of organisational policies for healthcare and lifestyle decision-making among Australian aged care providers', (2019), vol 38(S2), *Australasian Journal on Ageing*, pp 90–7.

145 *Quality of Care Principles 2014* (Cth) Part 5, Schedule 2 'Aged Care Quality Standards', 'Standard 1'; see Australian Government Aged Care Quality and Safety Commission, *Guidance and Resources for Providers to support the Aged Care Quality Standards,* (Aged Care Quality and Safety Commission, March 2021) 8.https://www.agedcarequality.gov.au/sites/default/files/media/Guidance_%26_Resource_V14.pdf

146 https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-3a_0.pdf)

147 Cheryl Tilse & Jill Wilson, 'Recognising and responding to financial abuse in residential aged care', (2013), vol 15(3), *The Journal of Adult Protection*, pp 141–52; Kari Lislerud Smebye, Marit Kirkevold & Knut Engedal, 'How do persons with dementia participate in decision-making related to health and daily care? A multi-case study', (2012), vol 12(1), *BMC Health Services Research*, pp 241–241.

148 Cheryl Tilse, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, 'Managing older people's money: assisted and substitute decision-making in residential aged-care', (2011), vol 31(1), *Ageing & Society*, pp 93–109; Christine Bigby, 'Known well by no-one: trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community', (2008), vol 33(2), *Journal of Intellectual & Developmental Disability*, pp 148–57; and in the United Kingdom: Kari Lislerud Smebye, Marit Kirkevold & Knut Engedal, 'How do persons with dementia participate in decision-making related to health and daily care? A multi-case study', (2012), vol 12(1), *BMC Health Services Research*, pp 241–241.

149 Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, 'Supported Decision-making: The current state of knowledge', report prepared for the Royal Commission into Abuse, Violence, Neglect and Exploitation of People with Disability, February 2022.

150 Craig Sinclair, Meredith Blake & Sue Field, *Supported decision-making in aged care: a policy development guideline for aged care providers in Australia*, Cognitive Decline Partnership Centre, 2018.

151 NHMRC Cognitive Decline Partnership Centre (CDPC). (2019). Supported Decision-Making in Dementia Care: Final Project Report. Sydney: NHMRC Cognitive Decline Partnership Centre. https://cdpc.sydney.edu.au Also this is available in the written submission tabled to the Aged Care Royal Commission: https://agedcare.royalcommission.gov.au/system/files/2020-06/WIT.0218.0001.0001.pdf

152 Gemma Carey, Eleanor Malbon, Sue Olney & Daniel Reeders, 'The personalisation agenda: the case of the Australian National Disability Insurance Scheme' (2018) vol 28(1) *International Review of Sociology* pp 1–15; Gemma Carey, Eleanor Malbon and James Blackwell, 'Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals' ,(2021), vol 80(4), *Australian Journal of Public Administration* pp 854-872.

153 Terry Carney & Fleur Beaupert, 'Public and private bricolage: challenges balancing law, services and civil society in advancing the CRPD supported decision-making', (2013), vol 36(1), *University of New South Wales Law Journal*, pp 175–201; John Chesterman, 'Modernising adult protection in an age of choice', (2014), vol 73(4), *Australian Journal of Public Administration*, pp 517–24; Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel & Jacinta Douglas, 'National disability insurance scheme plan decision-making: or when tailormade case planning met taylorism & the algorithms?', (2019), vol 42(3), *Melbourne University Law Review*, pp 780—812; Elyse Perry, Rebecca Waters & Angus Buchanan, 'Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability', (2019), vol 54 (3), *The Australian Journal of Social Issues*, pp 210–23; Office of the Public Advocate (Vic), *Decision Time: Activating the rights of adults with cognitive disability*, *Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, 2021, p 25; K Mavromaras, M Moskos, S Mahuteau, L Isherwood, A Goode, H Walton & J Flavel, *Evaluation of the NDIS: Final report*, National Institute of Labour Studies, Flinders University, 2018.

154 Christine Bigby, Mary Whiteside & Jacinta Douglas, *Supporting people with cognitive disabilities in decision-making – processes and dilemmas*, Living with Disability Research Centre, La Trobe University, 2015, pp 4; Bruce Alston, 'Towards supported decision-making: article 12 of the Convention on the Rights of Persons with Disabilities and guardianship law reform', (2017), vol 35(2), *Law in Context*, pp 21–39; Office of the Public Advocate (Vic), *Decision Time: Activating the rights of adults with cognitive disability*, Office of the Public Advocate (Vic), 2021; Emily Cukalevski, 'Supporting choice and control—An analysis of the approach taken to legal capacity in Australia's National Disability Insurance Scheme', (2019), vol 8(2), *Laws*, pp 1–19.

155 National Disability Insurance Agency, *National Disability Insurance Scheme Consultation Paper: Supporting you to make your own decisions.*, 2021, p 10.

156 Christine Bigby, Jacinta Douglas, Terry Carney, Shih-Ning Then, Ilan Wiesel & Elizabeth Smith, 'Delivering decision-making support to people with cognitive disability – what has been learned from pilot programs in australia from 2010 to 2015', (2017), vol 52(3), *Australian Journal of Social Issues*, pp 222–240.

157 David Tune, *Review of the National Disability Insurance Scheme Act 2013; Removing red tape and implementing the NDIS participant service guarantee* (2019), p 13 NDIS Act Review - final - with accessibility and prepared for publishing1 (dss.gov.au)

158 National Disability Insurance Agency, *National Disability Insurance Scheme Consultation Paper: Supporting you to make your own decisions*, 2021; National Disability Insurance Agency, *Companion Paper: Supporting you to make your own decisions*, *Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, 2021.

159 www.ndis.gov.au/community/working-towards-co-design

160 Emily Cukalevski, 'Supporting choice and control—an analysis of the approach taken to legal capacity in Australia's National Disability Insurance Scheme', (2019), vol 8(2), *Laws*, pp 1–19.

161 Office of the Public Advocate (Vic), *Decision Time: Activating the Rights of Adults with Cognitive Disability*, Office of the Public Advocate (Vic), 2021, p 29.

162 Dianne Winkler, Libby Callaway, Sue Sloan & Nadine Holgate, 'Everyday choice making: outcomes of young people with acquired brain injury after moving from residential aged care to community-based supported accommodation', (2015), vol 16(3), Brain impairment, pp 221–35.

163 Christine Bigby, Marie Knox, Julie Beadle-Brown, Tim Clement & Jim Mansell, 'Uncovering dimensions of culture in underperforming group homes for people with severe intellectual disability', (2012), vol 50(6), *Intellectual and Developmental Disabilities*, pp 452–67.

164 Michelle Jennett Browning, 'Developing an understanding of supported decision-making practice in Canada: the experiences of people with intellectual disabilities and their supporter', PhD Thesis, La Trobe University, 2018; Nandini Devi, Birgit Prodinger, Andrew Pennycott, Roja Sooben & Jerome Bickenbach, 'Investigating supported decision-making for persons with mild to moderate intellectual disability using institutional ethnography', (2020), vol 17(2), *Journal of Policy and Practice in Intellectual Disabilities*, pp 143–156.

165 Patrick McKearney, 'What escapes persuasion: why intellectual disability troubles 'dependence' in liberal societies', (2021), vol 40(2), *Medical Anthropology*, pp 155–68.

166 Jonathon Savery, 'Voting rights and intellectual disability in Australia: an illegal and unjustified denial of rights', (2015), vol 37(2), *The Sydney Law Review*, pp 287-300; K Nadakavukaren Schefer, Terry Carney, Rachele Cera, J Curran, S De Dycker, V Kühnel, J Lespérance, M Schulze, A Vasquez, C Viennet & H Westermark, *Persons with disabilities' right to autonomy and their right to vote: Australia, Austria, Canada, France, Germany, Italy, the Netherlands, New Zealand, Norway, Spain, Sweden, United Kingdom, United States*, Swiss Institute of Comparative Law, 2019.

167 Section 93(8)(a) *Commonwealth Electoral Act 1918* (Cth).

168 Jonathon Savery, 'Voting rights and intellectual disability in Australia: an illegal and unjustified denial of rights', (2015), vol 37(2), *The Sydney Law Review*, pp 287-300; K Nadakavukaren Schefer, Terry Carney, R Cera, J Curran, S De Dycker, V Kühnel, J Lespérance, M Schulze, A Vasquez, C Viennet & H Westermark, *Persons with disabilities' right to autonomy and their right to vote: Australia, Austria, Canada, France, Germany, Italy, the Netherlands, New Zealand, Norway, Spain, Sweden, United Kingdom, United States*, Swiss Institute of Comparative Law, 2019; see also recent advocacy from peak bodies: https://pwd.org.au/group-of-65-organisations-and-experts-call-for-reform-to-laws-that-stop-people-with-disability-from-voting/ https://www.barkuma.com.au/articles/voting-rights-for-people-with-intellectual-disability/ https://www.downsyndrome.org.au/voice/wp-content/uploads/sites/4/2020/03/IntellectualDisabilityandVotingpdf.pdf

169 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, 2014.

170 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, \2014.

171 Christine Bigby, Sophia Tipping, Emma Bould & Rebecca Thiele, *Final report: Strategies to support people with intellectual disabilities to participate in voting*, Living with Disability Research Centre, La Trobe University, 2019.

172 Christine Bigby, Sophia Tipping, Emma Bould & Rebecca Thiele, *Final report: Strategies to support people with intellectual disabilities to participate in voting*, Living with Disability Research Centre, La Trobe University, 2019, p 5

173 Services Australia, *Someone to deal with us on your behalf* <https://www.servicesaustralia.gov.au/individuals/topics/someone-deal-us-your-behalf/30251>

174 Robin Creyke, 'Whose pension is it? Substitute payees for mentally incompetent pensioners', (1991), vol 10(2), *University of Tasmania Law Review* pp 102-128, 104; Robin Creyke, *Who can decide? Legal decision-making for others*, Department of Human Services and Health, 1995.

175 *Guardianship and Administration Act 1990* (WA), *Guardianship and Administration Act 1995* (Tas), *Guardianship Act 1987* (NSW), *Guardianship and Administration Act 2000* (Qld), *Guardianship and Management of Property Act 1991* (ACT), *Guardianship of Adults Act* (NT), *Guardianship and Administration Act 2019* (Vic).

176 Meredith Blake, Cameron Stewart, Pia Castelli-Arnold & Craig Sinclair, 'Supported decision-making for people living with dementia: an examination of four Australian guardianship laws', (2021), vol 28 *Journal of Law and Medicine,* pp 389–420.

177 Christine Bigby, Jacinta Douglas & Elizabeth Smith, *'Considering human Rights in decision making: evaluation of the introduction of structured-decision Mmaking framework in the Public Trustee Queensland*', Living with Disability Research Centre La Trobe University, 2021 <https://documents.parliament.qld.gov.au/tp/2022/5722T272-39B6.pdf>

178 *Guardianship and Administration Act 2000* (Qld) s 11B, Principle 10; *Powers of Attorney Act 1998* (Qld), s 6C, Principle 10; *Guardianship of Adults 2016* (NT), s 4(4)(b).

179 Christine Bigby, Jacinta Douglas & Elizabeth Smith, *Considering human rights in decision making: Evaluation of the introduction of structured decision making framework in the Public Trustee Queensland*, Living with Disability Research Centre, La Trobe University, 2021.

180 *Guardianship and Administration Act 2019* (Vic), Part 4 for ‘Supportive guardianship orders and supportive administration orders’; s 9 ‘Decision-making principles’; *Powers of Attorney Act 2014* (Vic) Part 7 ‘Supportive attorney appointments’; *Medical Treatment Planning and Decisions Act 2016* (Vic) ss 31–35 for ‘support persons;’.

181 Terry Carney, ‘The changing nature of adult guardianship: oxymoron or reality?’ powerpoint presentation to Australian Guardianship and Administration Council Conference, (22 October, 2022 forthcoming)

182 VLRC, ‘Guardianship: Final Report’, Victorian Law Reform Commission, 2012 <https://www.lawreform.vic.gov.au/publication/guardianship-report-pdf-2/> [4.30].

183 National Council on Disability, ‘Beyond guardianship:toward alternatives that promote greater self-determination’, Washington, DC: National Council on Disability, 2018 <https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf>: pp 92–94; ‘Turning Rights Into Reality:How Guardianship and Alternatives Impact the Autonomy ofPeople with Intellectual and Developmental Disabilities’, National Council on Disability, 2019 <https://ncd.gov/sites/default/files/NCD_Turning-Rights-into-Reality_508_0.pdf>: pp 29–36

184 Office of the Public Advocate (Vic), *Decision Time: Activating the rights of adults with cognitive disability* Melbourne, 2021, pp v, 31, 55. Similar but unintended pressures are generated by personalisation of service delivery: see pp 39, 59

185 *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 14(1) (definition of “person responsible”); s *Guardianship Act 1997* (NSW) s 33A;Ben White, Lindy Willmott & Shih-Ning Then, ‘Adults who lack capacity: substitute decision-making’ in Ben White, Fiona McDonald & Lindy Willmott (ed), *Health Law in Australia*, Thompson Reuters Lawbook Co, 3rd ed, 2018, pp 207–270; Also, https://end-of-life.qut.edu.au/treatment-decisions/adults/state-and-territory-laws

186 Some jurisdictions such as Victoria and Queensland already have provisions which largely reflect this.

187 Terry Carney, ‘Adult guardianship and other financial planning mechanisms for people with cognitive impairment in Australia’ in Lusina Ho and Rebecca Lee (ed), *Special Needs Financial Planning: A Comparative Perspective*, Cambridge University Press, 2019, pp 3–29.

188 The most reliable figures are those reported from the survey by Cheryl Tilse, Jill Wilson, Benjamin P White, Linda Rosenman & Rachel Feeney, ‘Having the last word: will making and contestation in Australia’, University of Queensland, 2015.<https://www.ptg.act.gov.au/images/pdf/having-the-last-word.pdf>; see also Financial Lifestyle Partners, ‘Research reveals most Australians don’t have a Will’ https://www.flpartners.com.au/blog-article/research-reveals-most-australians-dont-have-a-will.

189 Part 3A of the *Social Security (Administration) Act* 1999 (Cth) ss 123A–123S; the Centrelink Guide to policy administration operationalises the scrutiny of capacity and consent at the point of application for a payment nominee: DSS, *Guide to Social Security Law* Department of Social Services <http://guides.dss.gov.au/guide-social-security-law>: [8.5.1], and the process for ensuring that the nominee understands their fiduciary responsibility and keeps records of payments made: [8.5.3].

190 Source: Services Australia Data and Analytics Division, 10 June 2022.

191 Amber Shultz ‘Kidnapped by the State’ *Crikey,* September 2021 (https://www.crikey.com.au/topic/kidnapped-by-the-state/?utm_campaign=SundayRead&utm_medium=email&utm_source=newsletter).

192 Thanks to AGAC, consistent data exists on the *flow* of new guardianship orders across the country (19,799 in 2020–21), roughly half of which appoint citizens and the other half the public guardian or public trustee: https://www.agac.org.au/assets/images/Annual-Report-on-Adult-Guardianship-Orders-2020-2021_2022-03-14-014828.pdf

193 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Sigh-Ning Then, Jacinta Douglas & Terry Carney, ‘The temporalities of supported decision-making by people with cognitive disability’, (2020), *Social*

&Cultural Geography, DOI: 10.1080/14649365.2020.1829689; Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel, Jacinta Douglas & Elizabeth Smith, 'Realising 'Will, preferences and rights': reconciling differences on best practice support for decision-making?', (2019), vol 28(4) *Griffith Law Review*, pp 357–379; for the ALRC 'Support Guidelines' see Australian Law Reform Commission, 'Equality, Capacity and Disability in Commonwealth Laws: Final Report', 2014, 12: '(1) General (a) Persons who require decision-making support should be supported to participate in and contribute to all aspects of life. (b) Persons who require decision-making support should be supported in making decisions. (c) The role of persons who provide decision-making support should be acknowledged and respected—including family members, carers or other significant people chosen to provide support. (d) Persons who require decision-making support may choose not to be supported. (2) Assessing support needs In assessing what support is required in decision-making, the following must be considered: (a) All adults must be presumed to have ability to make decisions that affect their lives. (b) A person must not be assumed to lack decision-making ability on the basis of having a disability. (c) A person's decision-making ability must be considered in the context of available supports. (d) A person's decision-making ability is to be assessed, not the outcome of the decision they want to make. (e) A person's decision-making ability will depend on the kind of decisions to be made. (f) A person's decision-making ability may evolve or fluctuate over time'

194 Christine Bigby, Mary Whiteside & Jacinta Douglas, *Supporting people with cognitive disabilities in decision making – processes and dilemmas*, Living with Disability Research Centre, La Trobe University, 2015, p 36.

195 Terry Carney, Christine Bigby, Shih-Ning Then, Elizabeth Smith, Ilan Wiesel & Jacinta Douglas, 'Paternalism to empowerment: all in the eye of the beholder?', (2021), *Disability and Society*, DOI: 10.1080/09687599.2021.1941781; Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton, Helen Radoslovich, Meera Gar & Susan Kurrle, 'Professionals' views and experiences in supporting decision-making involvement for people living with dementia', (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84–105; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, 'Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences', (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481

196 J Osburn, G Caruso, & W Wolfensberger, 'The concept of "best practice": a brief overview of its meanings, scope, uses, and shortcomings', (2011), vol 58(3) *International Journal of Disability, Development and Education*, pp 213–222.

197 Lucy Knox, Jacinta Douglas & Christine Bigby, 'Becoming a decision-making supporter for someone with acquired cognitive disability following traumatic brain injury', (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities,* pp 12–21; Christine Bigby & Jacinta Douglas, 'Supported decision-making' in Roger J Stancliffe, Michael L Wehmeyer, Karrie A Shogren & Brian H Abery (ed) *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan*, Springer International Publishing, 2020, pp 45–66; Deirdre Fetherstonhaugh, Laura Tarzia, Michael Bauer, Rhonda Nay, E. Beattie & lizabeth, '"The red dress or the blue?" How do staff perceive that they support decision-making for people with dementia living in residential aged care facilities?', (2016), vol 35(2), *Journal of Applied Gerontology*, pp 209–26; Craig Sinclair, Sue Field, Meredith Blake & Helen Radoslovich, 'An examination of organisational policies for healthcare and lifestyle decision-making among Australian aged care providers', (2019), vol 38(S2), *Australasian Journal on Ageing*, pp 90–7; Amanda Keeling, 'Supported decision-making: the rights of pople with dementia'', (2016), vol 30(30), *Nursing Standard*, pp 38–44; Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton & Helen Radoslovich, 'Professionals' views and experiences in supporting decision-making involvement for people living with dementia', (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84–105.

198 Lucy Knox, Jacinta Douglas & Christine Bigby, ''The biggest thing is trying to live for two people': spousal experiences of supporting decision-making participation for partners with TBI', (2015), vol 29(6), *Brain Injury*, pp 745–57; Lucy Knox, Jacinta Douglas & Christine Bigby, '"I won't be

around forever": understanding the decision-making experiences of adults with severe TBI and their parents', (2016), vol 26(2), *Neuropsychological Rehabilitation*, pp 236–60; Lucy Knox, Jacinta Douglas & Christine Bigby, '"I've never been a yes person": Decision-making participation and self-conceptualization after severe traumatic brain injury', (2017), vol 39(22), *Disability and Rehabilitation*, pp 2250–60; Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587–608; Amanda Keeling, 'Supported decision-making: The rights of pople with dementia'', (2016), vol 30(30), *Nursing Standard*, pp 38–44;

199 Christine Bigby & Jacinta Douglas, 'Examining complexities of support for decision-making practice' in Ishita Khemka & Linda Hickson (ed) *Decision-making by individuals with intellectual and developmental disabilities: Integrating research into practice*, Springer, 2022, pp 65–94.

200 Jeremy Dixon, Sarah Donnelly, Jim Campbell & Judy Laing, 'Safeguarding people living with dementia: how social workers can use supported decision-making strategies to support the human rights of individuals during adult safeguarding enquiries', (2021), *The British Journal of Social Work*, pp 1–18; Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision making by people with cognitive disability,' (2020), *Social &Cultural Geography*, DOI: 10.1080/14649365.2020.1829689; Jacinta Douglas & Christine Bigby, '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', (2020), vol 42(3), *Disability and Rehabilitation*, pp 434–41; Craig Sinclair, Susan Kurrle, Sue Field, Meera Agar, Kathy Williams, Romola Bucks, Josephine Clayton, Cameron Stewart, Meredith Blake, Kirsten Auret, Meredith Gresham, Angelita Martini & Helen Radoslovich, *Supported Decision-Making in Dementia Care: Final Project Report*, NHMRC Cognitive Decline Partnership Centre, 2019; Amanda Keeling, 'Supported decision making: The rights of people with dementia'', (2016), vol 30(30), *Nursing Standard*, pp 38–44.

201 Jacinta Douglas & Christine Bigby, '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', (2020), vol 42(3), *Disability and Rehabilitation*, pp 434–41; Craig Sinclair, Susan Kurrle, Sue Field, Meera Agar, Kathy Williams, Romola Bucks, Josephine Clayton, Cameron Stewart, Meredith Blake, Kirsten Auret, Meredith Gresham, Angelita Martini & Helen Radoslovich, *Supported Decision-Making in Dementia Care: Final Project Report*, NHMRC Cognitive Decline Partnership Centre, 2019; Amanda Keeling, 'Supported decision making: the rights of people with dementia'', (2016), vol 30(30), *Nursing Standard*, pp 38–44.

202 Paul Webb, Gavin Davidson, Rosalie Edge, David Falls, Fionnuala Keenan, Berni Kelly, Aisling McLaughlin, Lorna Montgomery, Christine Mulvenna, Barbara Norris, Aine Owens & Rebecca Shea Irvine, 'Key components of supporting and assessing decision making ability', (2020), vol 72, *International Journal of Law and Psychiatry*, 101613.

203 Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, 'Supported Decision-making: The current state of knowledge', report prepared for the Royal Commission into Abuse, Violence, Neglect and Exploitation of People with Disability, February 2022.

204 https://www.supportfordecisionmakingresource.com.au/

205 Criag Sinclair, Sue Field, K Williams, Meredith Blake, R S Bucks, K Auret, J M Clayton & Sue Kurrle, *Supporting decision-making: A guide for people living with dementia, family members and carers*. Cognitive Decline Partnership Centre, 2018.

206 For other published research on support for people with profound intellectual disability, see: Joanne Watson, 'Assumptions of decision-making capacity: the role supporter attitudes play in the realisation of article 12 for people with severe or profound intellectual disability', (2016), vol 5(6), *Laws*, doi:10.3390/laws5010006; Joanne Watson, Hille Voss & Melissa J Bloomer, 'Placing the preferences of people with profound intellectual and multiple disabilities at the center of end-of-life decision making through storytelling', (2019), vol 44(4), *Research and Practice for Persons*

with Severe Disabilities, pp 267–79; Joanne Watson, Erin Wilson & Nick Hagiliassis, 'Supporting end of life decision making: case studies of relational closeness in supported decision making for people with severe or profound intellectual disability', (2017), vol 30(6), *Journal of Applied Research in Intellectual Disabilities*, pp 1022–34.

207 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 598–608, 601; see also Agnieszka Jaworska & Winston Chiong, 'Supported decision-making for people with dementia should focus on their values', (2021), vol 21(11), *The American Journal of Bioethics*, pp 19–21.

208 Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, 'Supported Decision-making: The current state of knowledge': report prepared for the Royal Commission into Abuse, Violence, Neglect and Exploitation of People with Disability', February 2022, pp 19–20, 30.

209 Karrie A Shogren, Evan E Dean, Brad Linnenkamp, Sheida K Raley, Jonathan Martinis & Peter Blanck, 'Supported decision-making' in Ishita Khemka & Linda Hickson (ed) *Decision making by individuals with intellectual and developmental disabilities: integrating research into practice*, Springer, 2021, pp 21–45; Tal Araten-Bergman & Christine Bigby, 'Forming and supporting circles of support for people with intellectual disabilities – a comparative case analysis', (2021), *Journal of Intellectual & Developmental Disability* https://doi.org/10.3109/13668250.2021.1961049; Michelle Jennett Browning, 'Developing an understanding of supported decision-making practice in Canada: the experiences of people with intellectual disabilities and their supporter', (PhD Thesis, La Trobe University, 2018), 176–77; Christine Bigby, Mary Whiteside & Jacinta Douglas, 'Providing support for decision making to adults with intellectual disability: perspectives of family members and workers in disability support services', (2019), vol 44(4), *Journal of Intellectual & Developmental Disability*, pp 396–409; Karrie A Shogren, Evan E Dean, Brad Linnenkamp, Sheida K Raley, Jonathan Martinis & Peter Blanck, 'Supported decision-making' in Ishita Khemka & Linda Hickson (ed), *Decision making by individuals with intellectual and developmental disabilities: integrating research into practice*, Springer, 2021, pp 21–45

210 Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015.

211 Tal Araten-Bergman and Christine Bigby, 'Forming and supporting circles of support for people with intellectual disabilities – a comparative case analysis' (2022) 47(2) (2022/04/03) *Journal of Intellectual & Developmental Disability*, pp 177–189.

212 Mary Donnelly, 'Support relationships in law: framing, fictions and the responsive state' in Mary Donnelly, Rosie Harding & EzgiTaşçıoğlu (ed), *Supporting Legal Capacity in Socio-Legal Context*, Hart, 2022, pp 19–38.

213 *Powers of Attorney Act 2014* (Vic) Part 7.

214 Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, Supported decision-making: the current state of knowledge, report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, February 2022.

215 Terry Carney, 'Supported decision-making for people with cognitive impairments: an Australian perspective?', (2015), vol 4, *Laws*, pp 37-59, 41; Jacinta Douglas & Christine Bigby, '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', (2020), vol 42(3), *Disability and Rehabilitation*, pp 434–41

216 Marcus Sellars, Julien Tran, Linda Nolte, Ben White, Craig Sinclair, Deirdre Fetherstonhaugh & Karen Detering, 'Public knowledge, preferences and experiences about medical substitute decision-making: a national cross-sectional survey' (2021), *BMJ Supportive & Palliative Care* bmjspcare-2020-002619

217 Jacinta Douglas & Christine Bigby, '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', (2020), vol 42 (3), *Disability and Rehabilitation*, pp 434–441.

218 Mary Donnelly, ‘Support relationships in law: framing, fictions and the responsive state’ in Mary Donnelly, Rosie Harding & Ezgi Taşcıoğlu (ed), *Supporting Legal Capacity in Socio-Legal Context*, Hart, 2022, pp 19–38.

219 See for example: Social Policy Research Centre, *Skilled to thrive: support to make decisions that promote personal safety and prevent harm*, Social Policy Research Centre UNSW, 2017; see also project now launched by CID My Rights Matter https://cid.org.au/issues/my-rights-matter/

220 Edward L Deci & Richard M Ryan, ‘Self-determination theory’ in J D Wright (ed), *International Encyclopedia of the Social and Behavioral Sciences*, Elsevier Ltd, 2015, pp 486–91.

221 Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, ‘Supported decision-making: the current state of knowledge, report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability’, February 2022.

222 For instance, in relation to advance planning instruments in dementia, see: K A Sullivan, K Purser, K Graham, & L Parkinson, ‘Public awareness of legal decision-making capacity and planning instruments in dementia: implications for health care practitioners’, (2022), *Psychiatry, Psychology and Law*, pp 1–14.

223 Rosie Harding & Ezgi Taşcioğlu, *Everyday Decisions Project Report: Supporting Legal Capacity through Care, Support and Empowerment*, Birmingham Law School, University of Birmingham, 2017.

224 S Biggs, I Haapala, & A Carr, *Dementia in the public domain: voice and age-based perspectives on dementia, social disadvantage and public health campaigning*, University of Melbourne, 2019.

225 Margaret Bushko, ‘Toxic: A Feminist Legal Theory Approach to Guardianship’ (2022), vol 81 *Maryland Law Review Online,* p 141.

226 S Biggs, I Haapala, & A Carr, *Dementia in the public domain: voice and age-based perspectives on dementia, social disadvantage and public health campaigning*, University of Melbourne, 2019.

227 P Mittler, ‘The UN Convention on the Rights of Persons with Disabilities: implementing a paradigm shift’, (2015), vol 12(2), *Journal of Policy and Practice in Intellectual Disabilities*, pp 79–89.

228 *Thematic study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities*, United Nations, 2010.

229 Amanda Keeling, ‘Supported decision making: the rights of people with dementia’’, (2016), vol 30(30), *Nursing Standard*, pp 38–44.

230 Nina A Kohn, Jeremy A Blumenthal & Amy T Campbell, ‘Supported decision-making: A viable alternative to guardianship? (Capacity, conflict and change: Elder law and estate planning themes in an aging world)’, (2013), vol 117(4), *Penn State Law Review*, pp 1111–58, 1137.

231 Nina A Kohn & Jeremy A Blumenthal, ‘A critical assessment of supported decision-making for persons aging with intellectual disabilities’, (2014), vol 7(1, Supplement), *Disability and Health Journal*, S40.

232 Matthé Scholten, Esther Braun, Jakov Gather & Jochen Vollmann, ‘Combining supported decision-making with competence assessment: A way to protect persons with impaired decision-making capacity against undue influence’, (2021), vol 21(11), *The American Journal of Bioethics*, pp 45–47.

233 M C Dunn, I C H Clare & A J Holland, ‘Living ‘a life like ours’: support workers’ accounts of substitute decision-making in residential care homes for adults with intellectual disabilities’, (2010), vol 54(2), *Journal of intellectual disability research*, pp 144-160; Christine Bigby, Mary Whiteside & Jacinta Douglas, ‘Providing support for decision making to adults with intellectual disability: perspectives of family members and workers in disability support services’, (2019), vol 44(4), *Journal of Intellectual & Developmental Disability*, pp 45–66.

234 Terry Carney, ‘Searching for workable alternatives to guardianship for vulnerable populations?’, (2015), vol 1(1), *Ethics, Medicine and Public Health*, pp 113–19.

235 *Guardianship and Administration Act 2019* (Vic); *Powers of Attorney Act 2014* (Vic).

236 See for example: https://eapu.com.au/elder-abuse-helpline/; https://www.qld.gov.au/seniors/legal-finance-concessions/legal-support/legal-services; https://www.publicguardian.qld.gov.au/investigations/who-else-can-help/elder-abuse

237 For a general discussion in the context of legal frameworks see Shih-Ning Then, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1), *Sydney Law Review*, pp133–66.

238 Peter Bartlett, ‘At the Interface between paradigms: English mental capacity law and the CRPD’, (2020), vol 11, *Frontiers in psychiatry*, doi: 10.3389/fpsyt.2020.570735, p 10.

239 Antonio Martinez-Pujalte, ‘Legal Capacity and supported Decision-making: lessons from some recent legal reforms’, (2019), vol 8(4), *Laws*, doi:10.3390/laws8010004

240 Zachary Allen & Dari Pogach, ‘More States Pass Supported Decision-Making Agreement’, (2019), vol 40(1), *Bifocal: Journal of the ABA Commission on Law and Aging*, pp 159–61.

241 Piers Gooding, *A new era for mental health law and policy: Supportive decision-making and the UN Convention on the Rights of Persons with Disabilities*, Cambridge University Press, 2017, p 224.

242 Kristin Booth Glen, ‘What Judges Need to Know About Supported Decision-Making, and Why’, (2019), vol 58(1), *The Judges’ Journal*, pp 26–31, discussing the Texas law at 29.

243 Antonio Martinez-Pujalte, ‘Legal capacity and supported decision-making: lessons from some recent legal reforms’, (2019), vol 8(4), *Laws* doi:10.3390/laws8010004

244 Antonio Martinez-Pujalte, ‘Legal capacity and supported decision-making: lessons from some recent legal reforms’, (2019), vol 8(4), *Laws*, doi:10.3390/laws8010004; Marie Fallon-Kund & Jerome E Bickenbach, ‘New legal capacity laws and the United Nations Convention on the Rights of Persons with Disabilities: an overview of five countries in Europe’, (2017), vol 24(3), *European Journal of Health Law*, pp 285–310.

245 Alberto Vasquez Encalada, K Bialik & K Stober, ‘Supported Decision-making in South America: Analysis of Three Countries’ Experiences’, (2021), vol 18(10), *International Journal of Environmental Research and Public Health*, p 5204. https://doi.org/10.3390/ijerph18105204; Antonio Martinez-Pujalte, ‘Legal capacity and supported decision-making: lessons from some recent legal reforms’, (2019), vol 8(4), *Laws* doi:10.3390/laws8010004

246 *Powers of Attorney Act 2003* (NSW) ss 26–38, *Powers of Attorney Act 2014* (Vic) part 8, *Powers of Attorney Act 1998* (Qld) Chapter 6

247 Gali H Weissberger, Morgan C Goodman, Laura Mosqueda, Julie Schoen, Annie L Nguyen, Kathleen H Wilber, Zachary D Gassoumis, Caroline P Nguyen & Han S Duke, ‘Elder abuse characteristics based on calls to the National Center on Elder Abuse Resource Line’ (2020) vol 39(10) *Journal of Applied Gerontology*, pp 1078-1087

248 *Quality of Care Principles 2014* (Cth) Part 5, Schedule 2 ‘Aged Care Quality Standards’, ‘Standard 1’; see Australian Government Aged Care Quality and Safety Commission, *Guidance and Resources for Providers to support the Aged Care Quality Standards,*, Aged Care Quality and Safety Commission, March 2021, p 8. https://www.agedcarequality.gov.au/sites/default/files/media/Guidance_%26_Resource_V14.pdf

249 See: https://workforcecapability.ndiscommission.gov.au/sites/default/files/2021-08/NDIS-Workforce-Capability-Framework.pdf

250 Roy Sainsbury, ‘Administrative Justice, Discretion and the “Welfare to work” Project’, (2008), vol 30(4) *Journal of Social Welfare and Family Law*, pp 323–38; Michael Adler, ‘A Socio-Legal Approach to Administrative Justice’, (2003), vol 25(4), *Law & Policy*, pp 323–52; for a comprehensive review: Jerry L Mashaw, ‘Models of Administrative Justice’ in Joe Tomlinson, Robert Thomas & Marc Hertogh (ed), *The Oxford Handbook of Administrative Justice*, Oxford University Press, 2021, online DOI: 10.1093/oxfordhb/9780190903084.9780190903013.9780190903018

251 Aged Care Quality and Safeguards Commission, ‘Final Report ‘Care, Dignity and Respect’’, 2021. <https://agedcare.royalcommission.gov.au/publications/final-report>; K Carnell, K., & R Paterson (2017). *Review of National Aged Care Quality Regulatory Processes*. Retrieved from Canberra: https://agedcare.health.gov.au/quality/review-of-national-aged-care-quality-regulatory-processes-report

252 See *Medical Treatment Planning and Decisions Act 2016* (Vic); M Sheehan, Christine Bigby & Jacinta Douglas, (under review). ‘Preparing an advance care directive: a case study of person with intellectual disability and their supporter’ *Australian Journal of Social Issues*.

253 See for example Bigby who found the most effective type of future planning by parents was finding a ‘key succession person’ who could replace parents as primary decision supporters

of a person with intellectual disability: Christine Bigby, ‘Transferring responsibility: the nature and effectiveness of parental planning for the future of adults with intellectual disability who have remained at home until mid-life’, (1966) vol 21 *Journal of Intellectual and Developmental Disability*, pp 295–312.

254 *Guardianship and Administration Act 2019* (Vic) Part 4

255 Office of the Public Advovocate (Vic), ‘Decision Time: Activating the rights of adults with cognitive disability’, Office of Public Advocate (Vic), 2021, <https://www.publicadvocate.vic.gov.au/resources/research-reports/756-decision-time/file>: 114.

256 Amanda Keeling, ‘Supported decision-making: The rights of people with dementia’’, (2016), vol 30(30), *Nursing Standard*, pp 38–44.

257 “The law, in its majestic equality, forbids rich and poor alike to sleep under bridges, to beg in the streets, and to steal their bread”: Anatole France, *The Red Lily,* 1894.

258 Tal Araten-Bergman & Christine Bigby, ‘Forming and supporting circles of support for people with intellectual disabilities–a comparative case analysis’, (2021), *Journal of intellectual & developmental disability*; Christine Bigby, Sian Anderson & Nadine Cameron, ‘Identifying conceptualizations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability: a scoping review’, (2018), vol 31(2), *Journal of applied research in intellectual disabilities*, DOI: 10.3109/13668250.2021.1961049; see also current research project by Jacinta Douglas, Christine Bigby, Teresa Iacono & Rebecca Leeson, ‘M-com connect: maximising social connection and building relationships in the community’, https://www.latrobe.edu.au/lids/research/building-the-evidence-base-for-participation.

259 See: Vela Micro Board Association, https://velacanada.org/services/microboards/. Vela Canada, established in 1990, helps adults with a disability and their families to create small non-profit societies called microboards. Microboard members are friends and families who, with the individual, manage and advocate disability services for the individual and provide inclusion. Also https://zeroproject.org/practice/vela-microboard-association-canadabritish-columbia/)

260 David Plater, Lukas Price, Esther Richards & Mark Giancaspro, ‘New Avenues of Providing Effective Care: The role of microboards,’ (2021), vol 43(6) *The Bulletin: The Law Society of SA Journal*, pp 9–11 [Available at SSRN: https://ssrn.com/abstract=3880766]

261 Tim Stainton, R Morris, L Perry & Z Bahasdshah, ‘The impact of a community microboard program on social capital of persons with intellectual and developmental disabilities’ (2019) 63(7) *Journal of Intellectual Disability Research* S850 [Abstract of poster presentation The World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), Glasgow, Scotland

262 Michelle Browning, Christine Bigby and Jacinta Douglas, ‘Supported Decision making: Understanding how its conceptual link to legal capacity is influencing the development of practice’, (2014), vol 1(1) *Research and Practice in Intellectual and Developmental Disabilities*, pp 34–45, 37.

263 Sophie Nunnelley, ‘Personal support networks in practice and theory: assessing the implications for supported decision-making law’, Law Commission of Ontario, 2015 <https://www.lco-cdo.org/wp-content/uploads/2015/04/capacity-guardianship-commissioned-paper-nunnelley.pdf>: pp 17–20.

264 Sophie Nunnelley, ‘Personal support networks in practice and theory: assessing the implications for supported decision-making law’, Law Commission of Ontario, 2015 <https://www.lco-cdo.org/wp-content/uploads/2015/04/capacity-guardianship-commissioned-paper-nunnelley.pdf> p 22.

265 Sophie Nunnelley, ‘Personal support networks in practice and theory: assessing the implications for supported decision-making law’, Law Commission of Ontario, 2015 <https://www.lco-cdo.org/wp-content/uploads/2015/04/capacity-guardianship-commissioned-paper-nunnelley.pdf> p 58.

266 Terry Carney, ‘Adult guardianship and other financial planning mechanisms for people with cognitive impairment in Australia’ in Lusina Ho & Rebecca Lee (ed), *Special Needs Financial Planning: A Comparative Perspective*, Cambridge University Press, 2019, pp 3–29.

267 Sophie Nunnelley, ‘Personal support networks in practice and theory: assessing the implications for supported decision-making law’, Law Commission of Ontario, 2015 https://www.lco-cdo.org/wp-content/uploads/2015/04/capacity-guardianship-commissioned-paper-nunnelley.pdf pp 89–90

268 Sophie Nunnelley, ‘Personal support networks in practice and theory: assessing the implications for supported decision-making law’, Law Commission of Ontario, 2015 https://www.lco-cdo.org/wp-content/uploads/2015/04/capacity-guardianship-commissioned-paper-nunnelley.pdf pp 95ff.

269 Sophie Nunnelley, ‘Personal support networks in practice and theory: assessing the implications for supported decision-making law’, Law Commission of Ontario, 2015 https://www.lco-cdo.org/wp-content/uploads/2015/04/capacity-guardianship-commissioned-paper-nunnelley.pdf p 101.

270 Tamar Heller & Joe Caldwell, ‘Supporting aging caregivers and adults with developmental disabilities in future planning’, (2006), vol 44(3), *Mental Retardation*, pp189–202.

271 Rebekah Diller & Leslie Salzman, ‘Stripped of funds, stripped of rights: a critique of guardianship as a remedy for elder financial harm’, (2021), vol 24(2) *University of Pennsylvania Journal of Law and Social Change*, pp149–194, 185.

272 Carney, Terry, ‘Prioritising Supported Decision-making: Running on empty or a basis for glacial-to-steady progress?’ (2017), vol 6(18), *Laws* 1–14

273 National Disability Insurance Agency, *National Disability Insurance Scheme Consultation Paper: Supporting you to make your own decisions*, 2021.

274 Australian Law Reform Commission, ‘Equality, Capacity and Disability in Commonwealth Laws: Final Report’, 2014 <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/>

275 National Disability Insurance Agency, ‘Consultation Paper: Supporting you to make your own decisions’, 2021 <https://www.ndis.gov.au/community/have-your-say/support-decision-making-consultation>; NDIA, ‘Companion Paper: Supporting you to make your own decisions’, National Disability Insurance Agency, 2021 <https://www.ndis.gov.au/community/have-your-say/support-decision-making-consultation>

276 Terry Carney, Shih-Nng Then, Christine Bigby, Ilan Wiesel & Jacinta Douglas, ‘National Disability Insurance Scheme decision-making: or when tailor-made caseplanning met taylorism and the algorithms?’ (2019), vol 42(3), *Melbourne University Law Review*, pp 780–812; for a recent case involving specially adapted hearing aids, see *Re Brockett and National Disability Insurance Agency* [2022] AATA 214.

277 Michelle Browning, *To Investigate New Models of Guardianship and the Emerging Practice of Supported Decision Making*, Winston Churchill Memorial Trust of Australia, Canberra, 2011. https://www.churchilltrust.com.au/project/to-investigate-new-models-of-guardianship-and-the-emerging-practice-of-supported-decision-making/ Reports low uptake of Representation Agreements in British Columbia, although is partly explained by the opposition to Representation Agreements by the legal profession and health sector, which has meant minimal efforts at promoting this option. Not necessarily low demand by people with cognitive disabilities themselves; Nidus Personal Planning Resource Centre & Registry, ‘A Study of Personal Planning in British Columbia: Representation Agreements with Standard Powers’, 2010. Showed that there was a proportionately lower uptake of Representation Agreements among older adults; examined in: Blake, M, C Stewart, P Castelli-Arnold & Craig Sinclair, ‘Supported decision-making for people living with dementia: an examination of four Australian guardianship laws, (2021), vol 28(2), *Journal of Law and Medicine*, (2021), pp 389–420 at 419.

278 J Matt Jameson, Tim Riesen, Shamby Polychronis, Barbara Trader, Susan Mizner, Jonathan Martinis & Dohn Hoylel, ‘Guardianship and the potential of supported decision making with individuals with disabilities’ (2015), vol 40(1) *Research and Practice for Persons with Severe Disabilities,* pp 36–51; Roni Holler & Shirli Werner, ‘”Necessity is neither condemned nor praised”: social workers’ meanings of guardianship for disabled people’ (2022) vol 52 *British Journal of Social Work,* pp 98–115.

279 Roni Holler & Shirli Werner, ‘”Necessity is neither condemned nor praised”: social workers’ meanings of guardianship for disabled people’ (2022) vol 52 *British Journal of Social Work,* pp 98–115

280 See for example, a tendency for siblings to follow this path: Anna M Brady, Meghan M Burke, Trenton Landon & Kathleen Oertle, ‘Siblings of adults with intellectual and developmental disabilities: their knowledge and perspectives on guardianship and its alternatives’, (2019), vol 32(5), *Journal of Applied Research in Intellectual Disabilities*, DOI: 10.1111/jar.12597

281 Office of the Public Advocate (Vic) & VALID, Volunteer Programs of Support for Decision-Making: Lessons and Recommendations from the OVAL Project, VALID and Office of the Public Advocate, 2017

282 Meredith Blake, Cameron Stewart, Pia Castelli-Arnold & Craig Sinclair, ‘Supported decision-making for people living with dementia: an examination of four Australian guardianship laws’, (2021), vol 28(2), *Journal of Law and Medicine*, pp 389–420.

283 See generally https://www.britannica.com/topic/path-dependence; for discussion in the context of advance planning.

284 Roni Holler & Shirli Werner, ‘”Necessity is neither condemned nor praised”: social workers’ meanings of guardianship for disabled people’, (2022), vol 52, *British Journal of Social Work,* pp 98–115.

285 See initiatives of Qld’s Public Trustee and TAC: Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, ‘Supported Decision-making: The current state of knowledge, report prepared for the Royal Commission into Abuse, Violence, Neglect and Exploitation of People with Disability, February 2022.

286 Office of the Public Advocate (Vic) & VALID, Volunteer Programs of Support for Decision-Making: Lessons and Recommendations from the OVAL Project, VALID and Office of the Public Advocate, 2017

287 Gerard Quinn, ‘Legal culture and the CRPD’, in Emily Kakoullis and Kelley Johnson (eds), *Recognising Human Rights in Different Cultural Contexts*, Palgrave Macmillan, 2020, pp 19–44.

288 Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, ‘Supported decision-making: the current state of knowledge, report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability’, February 2022.

289 Meredith Blake, Cameron Stewart, Pia Castelli-Arnold & Craig Sinclair, ‘Supported decision-making for people living with dementia: an examination of four Australian guardianship laws’, (2021), vol 28(2), *Journal of Law and Medicine*, pp 389–420.

290 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences’, (2021), *Journal of Intellectual and Developmental Disability*, 10.3109/13668250.2021.1954481

291 Terry Carney, ‘Australian Guardianship Tribunals: An adequate response to CRPD disability rights recognition and protection of the vulnerable over the lifecourse?’, (2017), 10(Sp), *Journal of Ethics in Mental Health* https://jemh.ca/issues/v9/documents/JEMH%20article%20law%20theme%202%220final.pdf

292 Craig Sinclair, J Bajic-Smith, M Gresham, Meredith Blake, R S Bucks, Sue Field & Susan Kurrle, (2019). Professionals’ views and experiences in supporting decision-making involvement for people living with dementia’, (2019), vol 20(1) *Dementia,* pp 84–105. doi:10.1177/1471301219864849

293 Australian Government Department of Health, *Legislated Review of Aged Care 2017*; retrieved from https://www.health.gov.au/sites/default/files/legislated-review-of-aged-care-2017-report.pdf

294 Committee for Economic Development of Australia. (2021), *Duty of Care: Meeting the Aged Care Workforce Challenge*. Retrieved from https://www.ceda.com.au/Admin/getmedia/cc57cf82-06d8-4bfe-be20-63ed3dba6ccd/Aged-Care-Workforce-2021-FINAL_1.pdf

295 Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel & Jacinta Douglas, ‘National disability insurance scheme plan decision-making: Or when tailormade case planning met taylorism & the algorithms?’, (2019), vol 42(3), *Melbourne University Law Review*, pp 780—812.

296 Leslie Francis, ‘Supported decisions as the patient’s own?’, (2021), vol 21(11), *American Journal of Bioethics*, pp 24–26.

297 D Henderson, & Christine Bigby, ‘We were more radical back then: Victoria’s first self advocacy organisation for people with intellectual disability’, (2016), vol 18(1), *Health and History,* pp 42–66.

298 P Frawley, Christine Bigby, D Banfield, N Blythman, N Rosengrave, A Hiscoe & J Slattery, ‘Reinforce self advocacy: speaking up over the years. Melbourne, Living with Disability Research Centre, La Trobe University, 2023 http://arrow.latrobe.edu.au/store/3/5/0/8/9/public/35089.pdf

299 D Henderson, & Christine Bigby, ‘We were more radical back then: Victoria’s first self advocacy organisation for people with intellectual disability’, (2016), vol 18(1), *Health and History,* pp 42–66; P Frawley, Christine Bigby, D Banfield, N Blythman, N Rosengrave, A Hiscoe & J Slattery,

'Reinforce self advocacy: speaking up over the years. Melbourne, Living with Disability Research Centre, La Trobe University, 2023 http://arrow.latrobe.edu.au/store/3/5/0/8/9/public/35089.pdf

300 Roger J Stancliffe, Michael L Wehmeyer, Karrie A Shogren & Brian H Abery (ed) *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan*, Springer International Publishing, 2020.

Appendix A

Supported decision-making: The current state of knowledge

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List of tables

1. Introduction

This review has been prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. It covers the literature available on supported decision-making as it applies to adults with intellectual disabilities, acquired brain injuries, mental health conditions and dementia. Children were not within the scope of this review.

1.1 Method

The literature review process followed best practice for a ‘narrative review’. A narrative review process was chosen because the ill-defined and evolving nature of supported decision-making demanded the capture of a breadth of material (both in content and format) and a flexibility of approach.[1]

1.1.1 Database searching

A wide range of Australian and international databases in the Social Sciences, Sciences and Law were searched. These were: APA Psychinfo; CINAHL; Embase; Google Scholar; HeinOnline; Informit Australian databases – 9 of the 81 databases, ie A+Education, AGIS Plus Text, Asia Collection, Australian Public Affairs (APAFT), Families & Society Collection, Health Collection, Humanities & Social Sciences Collection, Indigenous Collection, New Zealand Collection; Medline; Proquest; Scopus; SSRN: Social Science Research Network eLibrary; Web of Science; Westlaw UK and Westlaw (International Materials).

We used a variety of search terms using boolean search strategies title plus abstract fields. Some of these were used in combination with the subject heading searches above. Terms used were:

- Administrator*
- article 12
- assist*
- assist [near] decision
- ‘assisted decision-making’
- brain [near] injury
- capacity
- conservator*
- decision*
- dementia
- ‘developmental disability’

- disabilit*
- guardian*
- ‘intellectual disability’
- ‘mental illness’
- ‘Mental [near] illness’
- support*
- support [near] decision
- ‘supported decision-making’
- ‘support for decision-making’
- ‘supported decision-making’

The following databases were searched both by free text (see above) and by subject heading:

- APA Psychinfo – from the thesaurus: ‘human rights’ ‘decision-making’, ‘decision support systems’, ‘guardianship’, ‘disability laws’, ’dementia’, ‘mental health’ ‘mental status’, ‘traumatic brain injury’, ‘intellectual development disorder’, ‘cognitive aging’.
- CINAHL – ‘decision-making’, ‘guardianship, legal’, ‘competence (Legal)’, ‘cognition disorders’
- EMBase – ‘decision-making’, ‘legal competence’, ‘disability’
- Medline – ‘mental competency’, ‘decision support techniques’, ‘decision-making’, ‘developmental disability’, ‘mentally ill persons’, ‘dementia’, ‘brain injuries’

Subject heading searching was combined with/added to with free text searching.

One team member reviewed the lists of references (up to possibly 2000 in a list) and excluded documents which were clearly unrelated – for example, automated artificial intelligence decision-making systems, or decision-making purely by clinicians. If there were too many unrelated documents, the search was narrowed.

Additional materials were sourced ‘by hand’ including from:

- Members of the research team;
- Reviewing bibliographies in leading articles;
- Reviewing published literature reviews; and
- Using Google Scholar to find where key articles had been subsequently cited.

Data base searching was limited to material published in a 10 year period – from 2011 to 24 September 2021. Some more recent materials were sourced through ‘hand searching’. There were no strict limits on the type of materials sourced. In particular, some grey material was included in the interests of capturing pilots/programs/tools that were still in progress, were not yet evaluated or had been informally implemented.

1.1.2 Results

The above process resulted in 656 items (following exclusion of duplicates). Two members of the team reviewed abstracts and excluded irrelevant material resulting in 542 items remaining. Following full text review the same two members excluded more items, resulting in 292 items remaining. As a result of ongoing ‘hand searching’ by team members further items were included to ensure currency and comprehensiveness, resulting in a final count of 322 items. The larger number of items in the bibliography reflects additional references that are referred to by way of providing background or context (ie including United Nations documents, annual reports, etc).

2. Background and Australian context

2.1 Historical setting

People with disabilities have long been denied autonomy and human dignity. Until the late twentieth century in Australia and other nations, many people with disabilities were placed in institutions and, together with many people who remained living with families, were denied the right to make decisions about their own lives. Reports about the consequent neglect, abuse and degradation of people with disabilities[2] led to a move towards community living and the promise of greater personal autonomy.

However, despite deinstitutionalisation, adults with cognitive disabilities are still often denied the right to make their own decisions. Adult guardianship regimes mean that a substitute (eg guardian, administrator, curator, conservator, attorney, tribunal or court) can make decisions *for* an adult with cognitive disability.[3] In addition, adults with mental health conditions can be treated involuntarily in mental health services or in the community, with decisions made for them by health practitioners, often against their expressed will. Decision-making by a substitute is generally legally justified on the basis that the person lacks decision-making capacity, and that substitute decision-making can protect their ostensible 'best interests'. Yet, substitute decision-making can significantly limit an adult's choice and control over their own lives, and their autonomous 'will and preferences' may not be respected. In legal terms this means they are denied legal capacity.

2.2 Human rights imperatives

The paternalism of guardianship and involuntary treatment led to human rights based endeavours to provide supports for people with cognitive disabilities to make their own decisions, and have their legal capacity recognised. The terminology used to describe the practice and law around these endeavours is by no means uniform; but the practical process is sometimes referred to as support for decision-making, while its recognition in legal frameworks is often referred to as supported decision-making.[4] In this review we adopt the term 'supported decision-making' to describe both the practice of support and its implementation via policies and formal frameworks.

Increasing recognition of the law and practice of providing supports for decision-making led to what has been hailed as a 'paradigm shift' in the *United Nations Convention on the Rights of Persons with Disabilities* ('CRPD').[5] The CRPD was adopted in 2006 and ratified by Australia in 2008. It includes a right for people with disability to have their legal capacity recognised equally with others, and an obligation for states to provide supports for exercising legal capacity.

Supported decision-making has been conceptualised as a way to ensure that an individual's 'will and preferences' are given effect in decisions about their own lives, in the same way that everyone else's decisions are realised. We note that there is no uniform definition of supported decision-making that is widely adopted and the term is open to different disciplinary understandings.[6] Indeed, the wide range of ways in which it is being interpreted in the literature in respect of different groups of people with disabilities, together with the number of initiatives that this review has revealed, demonstrate that supported decision-making is sometimes being used as an umbrella term for what is being perceived as more CRPD compliant practices.

2.3 Implementation challenges

Despite the promise of the CRPD, implementation of supported decision-making remains a challenge. In the practice sphere, several decision-making pilots aimed at developing and testing support practices have been completed in Australia, and this review identifies a handful of comparable endeavours internationally. In the legal sphere, some Canadian provinces began developing legislation in the 1990s ahead of the CRPD, and Australian states have taken a piecemeal approach to legislative reform since 2014. This review identifies the types of legislative reform that has taken place globally.

In 2014 the Australian Law Reform Commission released its report – Equality, Capacity and Disability in Commonwealth Laws ('ALRC Report').[7] The ALRC Report proposed the adoption of four national decision-making principles to be incorporated in Commonwealth legislation, for example relating to the National Disability Insurance Scheme ('NDIS'), as well as in state and territory laws (including guardianship and supported decision-making legislation). These four principles, drawn from human rights principles and article 12 of the CRPD,[8] can be summarised as:

1. Adults have an 'equal right to make decisions';
2. People who require it must be provided with access to supports for decision-making;
3. For people requiring supports, their 'will, preferences and rights…must direct decisions that affect their lives'; and
4. legal frameworks must contain safeguards to 'prevent abuse and undue influence' in decision-making.

These principles have been widely endorsed in Australia and recognised internationally.[9] Significantly, the ALRC Report coincided with the roll out of Australia's NDIS. The NDIS introduced a new system of individualised funding aimed at optimising individual participants' choice and control over disability service provision. A significant number of participants within the NDIS experience cognitive disabilities. People with an intellectual disability constitute approximately 28.5% of all NDIS participants over the age of 25.[10] The challenge still remains as to how supported decision-making principles can be effectively implemented in practice, and how they can be usefully recognised and supported by law.

3. Overlapping concepts and practice boundaries

A number of concepts and practices within disability and health care literature cut across or overlap with supported decision-making. These distinct concepts and practices are increasingly recognised to incorporate aspects of supported decision-making, but are in separate (albeit sometimes overlapping) bodies of literature. These include the following.

3.1 Substitute decision-making

This review does not focus on substitute decision-making. However, it is acknowledged that much of the literature considers substitute decision-making to be in opposition to the concept of supported decision making, where the supported person retains control of decision-making. The United Nations Committee overseeing implementation of the CRPD ('CRPD Committee') has stated that many forms of substitute decision-making should be replaced by supported decision-making.[11] Legally, there is a distinction between support and substitution, as responsibility and authority for a decision resides with different people depending on which approach is legally recognised.

However, as noted below at Section Supported decision-making *when a substitute decision-maker is in place*), this binary (legal) perspective hides the fact that the practice of supported decision-making is not necessarily incompatible with relationships where a substitute decision may result. This is particularly in the context of 'informal' supporters and substitute decision-makers who have no formal legal appointment. In practice, support and substitution are often viewed on a spectrum where some substitute decisions are considered a form of supported decision-making, rather than being in opposition to it.[12] The relevant marker of supported decision-making in practice, is that an individual's stated or perceived 'will and preferences' remain at the centre of the decision.

Even in cases where a decision is legally attributed to a substitute, the individual's will and preferences may remain central and may be reflected in the substitute's ultimate decision. This approach to substitute decision making, where a substitute provides support and ultimately makes a decision in accordance with the person's will and preferences, is referred to in the legal literature as a 'substituted judgment' approach. However, many recognise this approach as being at one end of a spectrum of supported decision-making. This can be contrasted with an approach where, instead, what the substitute perceives as the individual's 'best interests' guides the decision made. This approach is less compliant with article 12 CRPD. The substituted judgement approach is more aligned with the intent of the 'will and preferences' approach but has been found to be difficult to apply in practice.[13]

This review does not focus on these technical distinctions or the contentions around them. It recognises that in practice, supported decision-making exists on a continuum. The challenge with the legal frameworks (see below at Section 8. *Legal mechanisms of supported decision-making*) is that the law does not readily deal with the nuanced approach demanded in real life.

3.2 Advance directives

Advance directives aim to allow a person to plan ahead for medical care and treatment decisions for a time when they can no longer make their own decisions. Advance directives can be categorised as a form of supported decision-making, as it is a method by which a person can record their will and preferences. Much of the literature discussing the use of Psychiatric Advance Directives (PADs) for people with mental health conditions, explicitly embraces them as a tool of supported decision-making (see below at Section Psychiatric *advance directives/ statements (PADs)*). However outside of the PAD context, the literature on advance directives tends to less commonly recognise them as a tool of supported decision-making.[14] To the extent that it does, that literature is considered below.

3.3 Shared decision-making

Shared decision-making[15] is a concept and practice common in medicine, involving clinicians and patients sharing decisions about patients' treatment, recognising both the clinicians' medical expertise, and the patients' right to self-determination.[16] Particularly in the health care context, confusion may exist over differences and commonalities between shared and supported decision-making.[17] A key difference between supported decision-making and shared decision-making is that the decision under a supported decision-making model is not made jointly with healthcare professionals.

3.4 Advocacy

This very broad concept has been defined as speaking up for, and standing alongside individuals or groups to ensure their rights are recognised, respected and secured, when their voices are otherwise not heard or respected. This involves advocates 'listening to someone and trying to understand their point of view; finding out what makes them feel good and valued; understanding their situation and what may be stopping them from getting what they want…'.[18] However, the concept and practice of advocacy is distinct from supported decision-making as in many instances advocates work with a person when they have already made decisions about chosen directions but have difficulty implementing them. It is noted however that the role of statutory independent advocates in the context of people with mental health conditions has been more explicitly embraced as a mechanism of supported decision-making (discussed below at Section Independent *Patient Rights Advisors/Independent Advocates*).

3.5 Person centred planning

Person centred planning practices are sometimes viewed as implementing principles of supported decision-making.[19] Person centred planning originated in the USA in the 1990s outside service systems, as part of a wider movement of flexible approaches to change the lives of people with intellectual disabilities with higher support needs. It was widely adopted in the UK and embedded into service systems. It 'offers people who want to make a change a forum for discovering shared images of a desirable future, negotiating conflicts, doing creative problem solving, making and checking on agreement on action, refining direction whilst adapting action to changing situations, and offering one another mutual support'.[20]

3.6 Person centred care

In the last 15 years, the term ‘person-centred’ has also been used with increasing frequency in healthcare. In this context, it has been defined as the ability to meet a person’s needs, values or preferences, optimising the person’s experiences with care, and fully involving the patients and their perspectives in care.[21] In 2014, the UK Health Foundation identified four key principles of person centred care: ‘(1) affording people dignity, compassion and respect; (2) offering coordinated care, support or treatment; (3) offering personalised care, support or treatment’; and (‘4) supporting people to recognize and develop their own strengths and abilities to enable them to live an independent and fulfilling life.’[22] These principles are conceptualised as applying across all health care services including situations where ‘the person is highly dependent – for example, if they are unconscious or otherwise lack capacity’.[23] While the enabling principle has commonalities with supported decision making, person-centred care focusses on the partnership between health care professionals and patients, and more closely reflects the process of shared decision making described above (at Section 3.3 *Shared decision-making*).

3.7 Self-determination[24]

Under the CPRD self-determination is a right of all people with disabilities, and it has also been seen as a psychological need.[25] Some literature describes self-determination as a personal characteristic, being the skill or confidence to make choices and bring them into action. It can be related to causal agency theory, the ability to set goals, to plot a pathway towards a goal and the belief in one’s own ability to take action.[26] Another perspective on self-determination is to see it as a process, making choices and bringing them into action, which is influenced by systems that operate at various ecological levels.[27]

The above topics have only been included in this review to the extent that the research specifically identified supported decision-making as relevant.

3.8 Terminology

The literature reveals a vast range of supported decision-making initiatives across many disciplines, service system contexts and disabilities. The degree to which these initiatives have been suggested, implemented or assessed, varies considerably. Given this significant variation, this review has adopted the following terms.

Table 1 Terms used in this review

Term	Description
Supported decision-making initiative	A broad term used to capture any action specifically aimed at supported decision-making and which includes the following: supported decision-making tool, supported decision-making legal mechanism; supported decision-making pilot; supported decision-making program.
Supported decision-making tool	A tool that has been developed to assist in some aspect of implementing supported decision-making.
Supported decision-making legal mechanism	A mechanism that has been recognised within legal frameworks as a way that supported decision-making may (or must) be implemented in practice.
Supported decision-making pilot	A short-term pilot program or study that examines the implementation of supported decision-making mechanisms or tools in relation to supported decision-making for people with disabilities.
Supported decision-making program	An implemented longer-term program designed to embed supported decision-making into practice in various contexts.

In this review we refer to a person accessing supported decision-making as the ‘supported person’ or the ‘decision-maker’.

4. Common themes and differences across people with disabilities

There are several common themes in the literature on supported decision-making, applying across people with intellectual disabilities, ABIs, mental health conditions and dementia. This section identifies key commonalities and differences; the next section discusses the literature relating to each of the disabilities separately.

4.1 The relationship between the supporter and supported person

A common theme in the literature across all disabilities is the importance of the supporter-decision-maker relationship. To provide effective support for decision-making, ideally the supporter(s) should know the person well;[28] have a trusting, ongoing relationship,[29] and understand the person's health condition or impairment, to enable effective communication.[30] The supporter(s) should also have an attitude that the person they are supporting is capable of participating in decision-making, and are committed to creating opportunities for decision-making.[31]

The literature examining how support for decision-making occurs in everyday life also evidences the complexity of the relationship between the supported person and the supporter(s). The 'fluid' nature of the interactions between supporter and supported person was evident across different groups and contexts. There was a recognition that a person's needs for support can take different forms and can vary across the life span, becoming more or less acute, depending on the of the person's circumstances at the time a decision is being made. Indeed, the literature recognises that support needs depend on the unique combination – of the decision, the context, and the supporter in each instance – that can make it hard to generalise about the types of support needed for decision making.[32] There was recognition of different 'modes' of decision-making along a continuum from autonomous to making decisions on behalf of someone may be needed.[33]

4.2 Factors that influence supported decision-making

The following factors have been identified as influencing the nature and provision of support for decision-making.

4.2.1 Who provides support

Across all groups of people with disabilities, support for decision-making was sought from a variety of different people and professionals.

For people with dementia and ABI who were partnered, it was more common for spouses to provide support for decision-making.[34] For people with dementia, often spouses had a better knowledge of the adult's usual preferences as compared with other family members, and expressed greater comfort in responding to changes in the person's need for supported decision-making.[35] However, there was also reliance on other close family members, in particular if a spouse experienced deterioration in their own health.[36] In people with ABI this was more likely to be parents, siblings, friends or paid professionals, such as disability support workers and long term case managers.[37] There is also a body of evidence around parents in particular providing support for decision-making for their adult sons and daughters with intellectual disabilities.[38]

While close family and friends were often relied upon in the mental health context, Australian research has demonstrated that clinicians have an important role in supporting people with mental health conditions who are engaged in mental health services, to make decisions.[39] People with dementia will often need support from residential aged care facility staff,[40] people reliant on supported accommodation may rely on paid staff, and anyone engaging with the health system may seek support from professionals they interact with.

The wide variety of interactions by people with disabilities – with service providers in healthcare, community care, supported accommodation or residential aged care, and their interactions with the NDIA and other agencies – means that paid professionals and staff without professional qualifications will also be called upon to support decision-making.[41] This has implications in terms of the types of professionals and other staff who should have an awareness of, and be able to implement, supported decision-making laws (if relevant) and practice. This links to the need for appropriate training and education of staff in different service contexts.[42] As noted below (at Section 7. Service system contexts of supported decision-making), the issue of transient workforces in these contexts is one of continuity of support in decision-making for individuals.

Some people have multiple supporters providing decision-making support,[43] yet most pilots and training to date have assumed that there will be a 'primary' supporter for an individual[44] with that supporter having a role in coordinating other relevant people who may be involved in the decision.[45] This fits with how service delivery operates in health care and aged care settings where a single point of contact is normally established for communication (although, perhaps, of less application to people with intellectual disabilities who have a range of different supporters associated with each of the services they use). However, there are also models of support that are predicated on a group model of support (see below at Section 5.1.3 *Circles of support* and Section Microboards *(and other incorporated networks)*), although how these work in practice is still being explored.[46]

There is also recognition that for some people, there are no pre-existing networks or relationships which can be drawn on to offer support for decision-making. This problem remains a very significant issue and is discussed further below (at Section 10.1 Problems identified with supported decision-making).

4.2.2 Risk

Disability scholarship has often been critical of restrictive 'safeguarding' practices that aim to reduce risk for people with disability while compromising self-determination.[47] Much of this work draws on Perske's concept of the 'dignity of risk', which recognises that risk-taking can be an act of self-determination and 'healthy development', while over-protection and risk avoidance can keep people with disability from ‘becoming all they could become’.[48] The ALRC recognised that supported decision-making can help individuals to be empowered to ‘make decisions – even bad ones (acknowledging the dignity of risk)’.[49] The management of perceived risk to the supported person by supporters has been identified in some research as a tipping point whereby supporters can often move into substitute decision-making. Supporters’ concern that some imminent or future harm will come to the person being supported if their will and preference is enacted is the motivation to move into substitute decision-making.[50] This is particularly evident in some service system contexts (see below at Section 7. *Service system contexts of supported decision-making*). This is consistent with psychological studies of risk preferences for self- and other-oriented decision-making, that show that greater psychological and emotional ‘distance’ tends to lead to more risk-neutral preferences in decisions.[51]

4.2.3 Emotional load

The emotional load of providing decision-making support to a person with a disability has been identified in the literature.[52] Perhaps unsurprisingly, it has been found that the closer the supporter is to the supported person, the greater the emotional labour associated with providing support.[53] This is particularly so in the context of a long term relationship where family members are likely to be personally impacted by a decision and emotionally invested in the process and outcome.[54]

4.2.4 Perceived inabilities to understand decision and express preferences

All disability groups include people with severe cognitive impairments and high support needs who will have limited ability to understand a decision, potential options, or to communicate their wishes clearly or directly.

The literature identifies the issue of how to determine and act upon the will and preferences of people with high support needs (often referred to as ‘hard cases’) as particularly challenging.[55] The CRPD Committee has stated that where it is not possible to determine a person’s will and preference, a ‘best interpretation’ of their will and preference should be adopted.[56] But what this means in practice is the subject of debate.[57]

Bach and Kerzner have advocated for ‘facilitated decision-making’ which Devi describes as a last resort mechanism.[58] This means that a representative can be appointed to make a decision on behalf of the adult by considering their will and preferences.[59] Such a model was also recommended by the ALRC as a last resort legal mechanism.[60] However Devi is ultimately critical of this recommendation because it does allow for ‘best interests’ decision-making in some cases[61] and Carney describes it as substitute decision-making by another name.[62]

There is limited consideration in the literature of the actual practice of supported decision-making and how it should work for people with high support needs. In a first-hand account, Tracy describes supported decision-making with her son Nick who has significant physical and intellectual disabilities. She describes how decisions with ‘potentially serious implications’

– such as dietary choices, need for surgery, criminal behaviour, accommodation and unsafe activities must be taken by the supporter.[63] She notes that communication is at the core, so supporting him requires an ‘intimate understanding’ of his personality. She stresses it is very important that he make his own decisions, but that it is very complex. Strategies involve an ongoing dialogue, checking with him that you have understood, choosing the right place (not noisy or unsafe) and times, knowing that he is a visual learner, listening to him, being interested in him, giving him time and encouragement and noticing him.[64] She advocates for balancing a ‘duty of care’ with the ‘dignity of choice’.[65]

Watson’s small qualitative study of people with ‘severe and profound’ intellectual disabilities considered what supported decision-making may look like for them. Each adult and their support network participated in a supported decision-making process about which data were collected using observation, interviews, focus groups and questionnaires. Her findings demonstrated the importance of supporter responsiveness and having a positive perception of the adults they support.[66] Watson et al examined support for a similar group of people with profound intellectual disabilities in relation to making end of life decisions. They describe the importance of non-verbal communication[67] and also: ‘…[t]he importance of knowing a person with intellectual disability’s history and personal story through narrative approaches, particularly in relation to understanding their preferences...’[68]

Bigby et al’s study of parental decision supporters included family members of four people with high support needs. Their findings illustrated the significance of knowing the person well, combined with careful observation, to identify subtle changes in behaviour that signal preferences. Notably too, a strategy of coordinating, sharing and seeking information with other supporters or service users, was used to further understand preferences.[69]

It is apparent from research on how decision-making occurs in practice, that support and substitution are viewed as existing along a spectrum. As a consequence, supporters often move between supported and substitute decision-making depending on the context and decision to be made.[70] As discussed above, sometimes this could be because of some perceived risk, but often it was also because supporters had made an assessment that the person with the disability no longer understood or had the decision-making ability to make the decision themselves.[71] How supported decision-making should work in the context of people with disabilities with high support needs is particular in need of further research.

4.2.5 Active encouragement to be independent

Parental supporters, in particular, walked a line between providing substantial support and drawing back to allow increased independence of their sons and daughters who they supported. This was evident in relation to people with intellectual disabilities and ABI.[72] There was also evidence of supporters of people with mental health conditions voicing the need to step back to allow the supported person to take the initiative in managing their conditions (but also due to the emotional load experienced in acting as a supporter).[73]

4.2.6 Precedent autonomy

The issue of how much respect should be accorded precedent autonomy – that is, the wishes expressed by a person prior to impairments in decision-making abilities – is particularly relevant for people with dementia, mental health conditions and those who experience an ABI. The literature reveals tensions in the weight to be accorded to wishes expressed prior to disability as compared with currently expressed wishes[74] (see, for example, Section Conceptual *complexities and controversies*). This 'right to change your mind' is a difficult conceptual issue that results in problems in practice, particularly with respect to time- and decision-specific assessments of decision-making capacity, and the interpretation of advance care directives.

A further issue arises from the push for people to formalise plans for the future in advance planning documents, particularly in the context of risk management by organisations such as residential aged care facilities which often want such documents in place for residents. Such tools have been recognised as a way to communicate an individual's will and preference, however, as recognised below (at Section Supported *decision-making when a substitute decision-maker is in place*), support for completing such documentation may be needed. There is also a need to continuously revisit advance planning documents to ensure they still reflect a person's will and preferences. For example in the mental health context Knight et al state:

> We also found that people's expectations of decision-making could shift over the course of an episode of being unwell and getting better, and over their lifetime. Trust, self-expertise, and self-confidence were important features in understanding how participants' expectations changed over time.'[75]

Such changes in will and preferences also suggest that always giving priority to a previously expressed wish, even if formalised in documents, may not be consistent with supported decision-making. In addition, the practice of advance care plans being completed for a person by a family member or other substitute decision-maker, raises questions over whether such documents truly reflect the person's own will and preferences, and are potentially morally problematic.[76]

4.2.7 Supporters' strategies, practices and tools

Many strategies are used in the practice of providing support for decision-making. The most common include: the need to take time and not rush;[77] to consider communication needs and tailor communication to the person;[78] and to provide options from which the supported person might choose.[79] However there was also a recognised need for training, to build capacity in supporters to enable them to provide high quality supported decision-making.[80]

5. Literature overview for people with different disabilities

In this section, the literature in relation to the four main disability groups, people with intellectual disabilities, ABI, mental health conditions and dementia are considered. We recognise that every individual's decision-making abilities will vary dependant on their disability or health condition and other comorbidities, how they experience their disability and the level of social supports that are in place. However, generalisations are made in this section to summarise the literature.

While we have segmented the literature according to disability group, we also recognise that many people will have more than one impairment or health condition – for example a person with mental health conditions may also experience dementia as they age, people with ABI have a high incidence of mental health comorbidities, and some people with intellectual disabilities also have mental health conditions and a high proportion of people with Down Syndrome experience the early onset of dementia as they age.[81]

This section also reports on a range of disability group-specific supported decision-making initiatives that were identified in the literature. The range of initiatives generally came within the ambit of supported decision-making tools. Some tools were undergoing evaluation or had been evaluated through a pilot. However, most tools had little by way of publicly reported evidence demonstrating their effectiveness in improving support for decision-making for people with disabilities. Some tools were aimed at improving communication, so in and of themselves may only address one aspect of supported decision-making. However, they may prove to be an additional strategy that supporters might use (from a range of strategies) in offering effective support for decision-making.

5.1 Intellectual disabilities

People with intellectual disabilities (also known as 'intellectual and developmental disabilities' and 'learning disabilities') tend to have relatively stable cognitive abilities. They do not experience episodic loss of decision-making ability (more common in mental health conditions) or gradual decline (as experienced by people with dementia) unless they also experience dementia in mid or later life. However, people with intellectual disabilities are likely to continue to develop cognitive capacity throughout adulthood. People with intellectual disabilities are more likely than other groups to have received long term support from family members (particularly parents) and may live in the community or in supported accommodation. Although importantly, they do not all have strong or resourceful family support.[82] With 28.5% of NDIS participants over 25 experiencing intellectual disability, they are more likely to be participants in the NDIS than people with dementia or mental health conditions.

Supported decision-making with people with intellectual disabilities can be considered an established concept given that early supported decision-making initiatives in Canada were focussed on addressing the needs of people with intellectual disabilities.[83] People with intellectual disabilities (as well as those with mental health conditions and ABI) were explicitly considered within the ambit of the CRPD and some intellectual disability advocates were heavily involved in its drafting.

5.1.1 Conceptual complexities and controversies

One issue of relevance to all conditions, but which has been discussed in the context of qualitative research involving people with intellectual disabilities, is how the terms ‘will’, ‘preference’ and ‘rights’ should be interpreted in providing supported decision-making. In relation to people with intellectual disabilities, Carney et al raise the issue of how to tell the difference between drawing out new options and a supporter actually imposing a view. Observation of adults and supporters making decisions indicates that there is ‘*some* degree of interpretation involved in most instances of support’.[84] As discussed below (at Section Mental *health conditions*), similar issues arise, although more likely episodically or at crisis points, for people with mental health conditions who experience involuntary treatment. Wiesel et al have also identified supporters’ difficulty in distinguishing and prioritising between short term preferences versus long term life values.[85] Supporters may ‘misread’ a person’s wishes,[86] or impose their own visions of what they hope life will be like for the person they support,[87] particularly in the absence of guidance around how to provide effective support.

Another issue relating to decision-making and people with intellectual disabilities is informal substitute decision-making occurring under the guise of supported decision-making.[88] Domestically, this may occur more in the course of daily support given by paid and unpaid supporters than in relation to what may be perceived to be larger or more significant life decisions. This practice of informal substitute decision-making may often go unnoticed or unremarked upon within families, particularly when adults with intellectual disabilities have parents who have always made decisions for them from childhood into adulthood.[89] This can occur particularly where issues involving potential risk to an individual are raised.[90] Such ‘informal’ substitute decision-making, may not place the person’s will and preferences at the centre of a decision. As well as occurring in Australia, it may also be prevalent in some countries where formal guardianship mechanisms are not commonly used and is considered a violation of the CRPD.[91] Also from a systemic perspective, there is the need to ensure that supported decision-making does not simply allow substitute decision-making under a new name.[92]

5.1.2 What supported decision-making looks like for people with intellectual disabilities

There is a growing body of literature that examines what supported decision-making looks like in practice with people with intellectual disabilities. Most of this comes from empirical observational and interview data with supporters and people with intellectual disabilities who are being supported.

The provision of supported decision-making is generally recognised as a dynamic process between supporter(s) and the decision-maker. It is complex, can be resource intensive and is highly individualised depending on the decision, the supported person’s needs and abilities, and supporters’ values and capabilities.[93] The literature emphasises that for effective support for decision-making there needs to be a relationship of trust between the supporter and decision-maker.[94] Improved support is often achieved when the supporter knows the decision-maker well, but there is emerging evidence of good practice also in newly formed relationships if such a relationship can be fostered.[95] However, as noted below, even in trusting relationships, supporters can seek to influence (sometimes strongly) the decisions being made.[96]

The literature demonstrates that support for decision-making comes from different people in different contexts. As already noted, family members – particularly parents, sometimes siblings[97] – have often been found to have an important role to play in supporting a person with intellectual disabilities to make decisions.[98] In addition, Devi[99] and Bigby et al[100] provide evidence of paid workers and managers acting as supporters in the context of disability support service provision. Devi notes that person centred planning meetings were seen as a 'prime example of a type of supported decision-making'.[101] It has been recognised that health care workers and particularly clinicians also have a role to play in supporting decision-making for people with intellectual disabilities.[102]

The types of strategies reported as being adopted by supporters were wide ranging, and included: planning, breaking decisions down, clarifying information, minimising anxiety, choosing when and how to have discussions, helping with problem solving, explaining risks, and creating opportunities.[103] To assist with decision-making, supporters often sought to: create decision-making opportunities; provide education about the practicalities and consequences of different choices;[104] and narrow down options. Supporters paid particular attention to the communication needs of the supported person, ensuring that they listened and engaged with them.[105] Augmentative and alternative forms of communication may be needed such as signing, assistive technologies, object references or facial expressions.[106] Self-reflection and review by supporters was considered essential, given the breadth of decisions that could be made, the unique combinations of considerations raised and the variety of people impacted or involved.[107]

How support is provided and what is looks like in practice will be influenced by the values of the supporter, but also by the context of individual decisions. For example, an Australian study shows parents of adults with intellectual disabilities moving between providing empowering support, to acting paternalistically, depending on the decision and context.[108] Similar findings that show a continuum of supportive practices are demonstrated in other Australian studies.[109] One of the factors that often drove practice along this continuum was perceived risk. Parents, in particular, tend to move from a supportive position to one where they restrict options or make decisions as a substitute to ensure safety. Werner and Chabany conducted focus groups on decision-making and noted in relation to people with intellectual disabilities that:

> …parents involved their children in decisions, but guided them in a direction that was correct according to the parent's perception. Thus, parents recognised the importance of their children experiencing a feeling of independence, but they did not think that it was right to give them full independence in decision-making, especially regarding complex or important decisions where the need to protect them overcame the value of independence.[110]

Similar findings where parents have either sought to actively influence, guide or replace a person with intellectual disabilities' decision have been reported elsewhere.[111] However, rather than simply being viewed as inappropriate influence or substitute decision-making, sometimes these practices were aimed at expanding the horizons for the person with disability or creating future opportunities for that person to exercise their self-determination.[112] A New Zealand study asked 15 people with intellectual disabilities how other people could help them to make choices. It found that for the most part family and staff 'could be helpful, but also that they could get in the way of people making their own choices...' or that sometimes staff were too busy to help them.[113] These findings demonstrate the complexity of the task of the supporter in weighing current and future 'will and preferences', particularly where more independence is sought by the person in the longer term.

The literature also demonstrates that there are certain categories of decisions where it may be more difficult for a person with a disability to access good support for decision-making. There was evidence in England that there is less support available for more complex decisions as compared with 'everyday' decisions.[114] Conversely, the opposite was found to be true in Australia where qualitative research showed that small decisions, viewed as inconsequential by supporters, were often made in circumstances where no supported decision-making was offered.[115] As discussed below (at Section Gender, *sexuality and people who identify as LGBTIQ*), support for decision-making in relation to decisions of an intimate or sexual nature was often poor or not available. In Canada, the Canadian Centre for Elder Law found that supported decision-making was not commonly used in relation to investment decisions for people with intellectual disabilities or dementia. Some perceived barriers were concerns about who was responsible for the decision and if undue influence was present as well as privacy concerns by institutions in discussing a person with disability's case with a supporter.[116]

5.1.3 Intellectual disabilities (non-legal) supported decision-making initiatives

A number of non-legislative supported decision-making tools and mechanisms were identified in the literature that were aimed at addressing aspects of supported decision-making for people with intellectual disabilities.

Guides for supporters

A number of 'guides' to supported decision-making have been developed by organisations both domestically and internationally. Some of these are particularly aimed at parents of adults with disabilities[117] and can include a pro forma supported decision-making agreement (which may or may not have any legal force depending on the laws of the jurisdiction) that can be filled out by decision-makers and their supporters.[118]

Circles of support

One model of support known as circles of support, or 'circle of friends', 'personal support network' or 'support circles' has been characterised by Nunnelley as having the following features: a group of people coming together on a voluntary basis to support a single person through relationships of trust.[119] The informal version of this practice, which will vary in terms of aims, strategies and practice between circles can occur without the need for any legal structure and can be used to support the person generally, but also as a mechanism to provide support for decision-making.[120] Generally the evidence about circles of support as an effective means of providing supported decision-making is limited.[121] However, having a group of people available to provide support has been suggested as providing informal checks and balances on inappropriate supporter behaviour.[122] This perhaps has potential to act as a safety net for adults with disabilities that may ward against abuse, neglect and exploitation. However, it has also been found that some circles of support are established to support parental decision-making rather than that of the person with disability.[123] See below (at Section Microboards *(and other incorporated networks)*) for discussion of where groups of supporters are formalised into a 'microboard' or incorporated entity.

WHO QualityRights

The focus of this World Health Organisation ('WHO') program is much broader than just supported decision-making. The full program of modules forms a practical tool for implementing human rights standards, and contains training materials including course slides and guidance for delivery.

There is an advanced education module on 'Realising supported decision-making and advance planning', aimed at 'challeng[ing] existing misconceptions that underpin the denial of the right to exercise legal capacity for people with psychosocial, intellectual or cognitive disabilities.'[124] This module consists of seven topics, taking approximately fifteen hours to deliver. It provides information about the human rights context and teaches participants how negative assumptions about people with disabilities can affect their right to make decisions. It explains the differences between substitute and supported decision-making; endorses a supported decision-making approach; and explains how to use advance planning tools to ensure people's will and preferences are respected.[125] The training uses case studies and promotes discussion amongst participants. The entire program (as opposed to this single module) has been implemented and evaluated in some countries, showing encouraging results.[126]

La Trobe Support for Decision-making Practice Framework ('La Trobe Framework')

This evidence-based framework forms the basis for education and training for supporters to provide effective decision-making support to people with intellectual disabilities and ABI. Its effectiveness has been evaluated in three pilots (discussed below at Section *Supported decision-making pilots – with published results and/or evaluations*), including one sponsored by an Australian Research Council ('ARC') Linkage grant funded pilot. The discussion here is limited to describing the La Trobe Framework and summarising peer reviewed publications relating to it.

The La Trobe Framework was developed through a research program modelled on the Medical Research Council four-phase approach to development and evaluation of complex interactions.[127] The research program explored the processes of support for adults with intellectual disabilities or ABI in decision-making, and led to the formulation of seven steps that are underpinned by three principles.[128] The seven steps are summarised as:

1. Knowing the person
2. Identifying and describing the decision
3. Understanding a person's will and preferences about the decision
4. Refining the decision and taking account of constraints
5. Considering whether a self-generated, shared or substitute decision is to be made
6. Reaching the decision and associated decisions
7. Implementing the decision and seeking advocates if necessary.[129]
8. The three principles of practice for supporters using the La Trobe Framework are:
    - commitment (that is, having a relationship with the person and commitment to upholding their rights);
    - orchestration (the primary supporter leads and coordinates support, draws in other supporters and mediates any differences), and
    - reflection and review (by the supporter to ensure transparency and accountability in their role).

Supporters also need to be able to implement a range of strategies that suit the person they are supporting.[130]

Findings from the ARC funded project confirmed the complexity of the supporter/decision-maker relationship and the emotional investment that most supporters put into providing support.[131] However, having a structured approach to supporting decision-making was found to be helpful.[132] Training provided a catalyst for parents to reflect and rethink their perspectives of how they approached decision-making with their sons or daughters with intellectual disabilities and for building awareness of their own influence over decisions.[133] The authors conclude the mentoring or other strategies should accompany the training to assist parents to implement supported decision-making.[134]

In an analysis of a subset of the qualitative findings from parent supporters of adults with intellectual disabilities, Bigby et al concluded that:

> The training and associated mentoring influenced the thinking and actions of parents, helped them to apply the Framework to their individual context, and gave them a reference point for their support practice. Acting as a catalyst for reflection, the training helped parents to realise how much they influenced their son or daughter's decision-making and the difficulties of maintaining rights-based support. In turn, such realisations helped parents see the value of self-reflection and commit to changing aspects of their support.[135]

These conclusions are borne out in the quantitative data from the slightly larger group of parent supporters. Using the Decision Support Questionnaire, significant changes in the hypothesised directions were found to the strategies used by parents, indicating a shift to practice more consistent with rights and supported decision making. There have been similar results from two pilot studies (see below at Section Supported *decision-making pilots – with published results and/or evaluations*) where the La Trobe framework or a modified version, was embedded into training for supporters.[136] Following training in both studies, supporters reported significantly increased confidence in providing support for decision-making as well as a change in support strategies more consistent with good supported decision-making practices in their interactions with their clients.[137]

5.2 Acquired brain injury (ABI)

ABIs (also called traumatic brain injuries) can be acquired at any point in a person's life. ABIs are '… associated with a range of changes across physical, cognitive, emotional and behavioural domains'.[138] Such changes may include: 'increased levels of stress and strain' and 'poorer mental health'.[139] This group are more likely to be participants in the NDIS than those with dementia or mental health conditions, although some will be covered by traffic accident insurance schemes such as the TAC in Victoria and iCare in NSW.

When compared with literature on supported decision-making for people with intellectual disabilities, the evidence base for people with ABIs is quite limited.

5.2.1 Conceptual complexities and controversies

A unique feature of cognitive disability associated with ABI compared with other disabilities is the sudden impact of the brain injury on the person and the reconstruction of their identity that often follows. People with an ABI may, similar to people with dementia, have made decisions mostly independently prior to their injury. Some commentators have assumed (particularly in the mental health and dementia context) that a person's wishes or 'will' can be ascertained by considering past preferences and enacted decisions.[140] However, as noted by Wiesel et al this does not necessarily apply to people with an ABI:

> [I]s a person's true will evident in their decisions before their ABI, apparently free of any distortions associated with the injury? Or, alternatively, does the injury represent such a radical discontinuity in one's identity, that their pre-injury preferences tell little about their post-injury will? Indeed, many people with ABI experience an ongoing process of reconstruction of self-identity marked by a temporal framing of 'before' and 'after' the injury
>
> … After an injury, many people with ABI continue to self-identify with personal attributes or characteristics from before the injury, alongside some newly recognised attributes shaped by experiences after the injury. Yet, the injury and its consequences often mark a significant temporal boundary – or discontinuity – in terms of personal goals. After their injury, striving to live well with their impairment, many people reassess their personal goals which continue to change over time.[141]

As a consequence, one complexity for supporters of people with ABI who knew the person before their injury, is grappling with the extent to which the person's psychological and emotional self has changed since the injury.

5.2.2 What supported decision-making looks like for people with ABI

Most of the work has been done in Australia and Canada with research mostly consisting of qualitative studies with small numbers of participants with ABI and those who provide supported decision-making. Some further research has included people with ABI alongside people with other disabilities in the context of examining supported decision-making.[142]

Effective supported decision-making has been identified as being particularly helpful for those with ABI to develop and maintain a positive self-concept.[143] People with ABI have identified that having a person who understands their condition and knows them well is important.[144] Knox et al's study described how participants with ABI liked to be able to choose supporters depending on the decision and their needs, describing supporters as taking on the following roles in providing effective decision-making support: creating opportunities for decision-making, providing expert advice, acting on their behalf and providing motivation and encouragement.[145] This study suggests that it can be important for supporters to understand the changes that have occurred in the person since the injury occurred and how different the person may be as a consequence.[146] The importance of parental supporters and the supported person having a shared vision of the person's future was noted to be central to a successful parent-adult support relationship.[147]

Some research tended to show that supporters who considered that they knew decision-makers with ABI well, were attuned to when environmental or contextual factors might compromise their decision-making abilities, and consequently may be aware of when more decision-making support was needed. For example, where decision-makers were put in time pressured or difficult environments and asked to make decisions, this could compromise decision-making abilities as compared with a structured and calm environment.[148]

The need for training and education and support for supporters of those with ABI has been identified in these studies,[149] as was health care professionals' role in providing supported decision-making.[150] One UK study identified potential deficits in professionals' understanding of ABI and how that affected a person with ABI being able to make decisions. This was particularly the case for professionals who had transient or short term interactions (for example, for capacity assessments) with a person with ABI as compared with case managers who had a longer term relationship and knew an individual better.[151]

5.2.3 ABI (non-legal) supported decision-making initiatives

The La Trobe Framework (discussed above at Section 5.1.3 *La Trobe Support for Decision-making Practice Framework ('La Trobe Framework')*) is an evidence-based program of training for supporters of people with ABI or intellectual disabilities. It has been implemented by a small number of TAC coordinators who underwent the training and who have clients with

ABI (see further below at Section *Supported decision-making pilots – with published results and/or evaluations*). The qualitative and quantitative results from that small study demonstrate that training in the La Trobe Framework had a significant impact on supporters' confidence and demonstrated a significant shift in supporters' reported strategies towards effective supported decision-making practices in dealing with their clients with ABI.[152]

5.3 Mental health conditions

The wide variety of mental health conditions and the many ways in which these are experienced, mean that decision-making processes and the needs of people with mental health conditions will vary considerably. Many people with mental health conditions experience no issues with their decision-making abilities, or else successfully manage decision-making informally. For others, episodic or ongoing mental health conditions are experienced as having a severe impact on their lives and associated with a high need for supported decision-making.

In general, it is possible to identify features of mental health conditions which distinguish them from intellectual disabilities, ABIs and dementia. Mental health conditions are more likely to have a changing or fluctuating impact on a person's ability to make decisions. Some mental health conditions are characterised by episodic periods where greater intervention and treatment by the State occurs. During these 'crisis' episodes there is more likely to be engagement with a specific section of the healthcare system where health professionals have distinct roles within a more regulated environment.

Literature relating to supported decision-making in the context of mental health conditions is burgeoning. However, as noted by Wilson, supported decision-making can be seen as a 'cognitive disability concept which has been expanded to the mental health context'.[153] Themes, conceptual understandings and supported decision-making initiatives tend to be distinct for this group from those that arise in relation to other disabilities. These differences may be partly attributed to the separate and distinct legal frameworks that many countries have for mental health treatment; and the fact that coercion and involuntary treatment has been a characteristic of treatment provision.

5.3.1 Conceptual complexities and controversies

As noted above (at Section 3.*Overlapping concepts and practice boundaries*), there are other concepts and practices that intersect and overlap with support for decision-making practices. Some specific to mental health but not the focus of this review are noted by Gooding as including 'recovery-oriented practice' and 'trauma-informed approaches'.[154] Some confusion may also arise due to the inclusive way in which the term 'supported decision-making' is being used. As noted by Davidson et al, in:

> international human rights law, 'supported decision-making' is one constitutive element of 'support to exercise legal capacity,' and refers to a person making a decision on his or her own behalf, with support in order to exercise his or her legal capacity.[155]

It is apparent in the mental health literature that sometimes a discussion of a 'supported decision-making paradigm' is taken to mean general compliance or consistency with CRPD article 12 requirements.

One debate in the literature that has particular relevance for mental health has been whether it is possible to comply with article 12 CRPD within substitute decision-making arrangements – particularly compulsory psychiatric treatment laws – if these are underpinned by human rights principles including respecting an individual's will and preference.[156] The conflicting views about this have been referred to as the 'Geneva Impasse'.[157]

The CRPD Committee's view is that substitute decision-making regimes including 'mental health laws that permit forced treatment' must be abolished and replaced by supported decision-making arrangements.[158] However, this position has been criticised by commentators (and particularly clinicians) who consider that this can lead to a person's needs being unmet.[159]

As already mentioned, difficulties arise in how we interpret and operationalise respecting a person's will and preference, including in the context of people with severe mental health issues.[160] One point of debate is whether within a supported decision-making framework, a person's 'will' – that is, long held personal values – should be given precedence over their momentary 'preferences' during an episode of mental ill health.[161]

5.3.2 What supported decision-making looks like for people with mental health conditions

Evidence in the literature tends to merge discussions of 'general' supports provided to assist a person with a mental health condition to participate in daily life, and support for decision-making specifically. As recognised by Wildeman, there are links between how supports in other areas of a person's life can impact on or ease involvement in decision-making:

> … supported decision-making in relation to psychiatric treatment – which arguably entails a right to a meaningful range of therapeutic options as well as supports for the exercise of choice among those options – is one piece of a broader picture of what it means to promote full social inclusion of persons with disabilities.[162]

However, in this review we have not focussed on broader discussions of general supports.

An ARC Linkage funded study into mental health and supported decision-making has explored what supported decision-making means, and how it is experienced, by people with mental health conditions, health care professionals and family supporters. Through examining twenty-nine narrative interviews with people diagnosed with mental illness, it was found that participants were likely to hold one or more of four narrative positions.[163] These four positions were in turn likely to affect how each individual preferred to be supported. They were:

Inward Expert ('presenting the self as an expert in relation to one's own experience');

Outward Entrustor (‘those who predominantly looked to medical expertise for guidance‘ in interpreting their own experiences);

Self-Aware Observer (those for whom agency was reconstituted in the context of the illness’ rather than a loss of self); and

Social Integrator (those who placed importance on ‘social integration’, and social relationships as an important part of their lives).

The researchers theorised that different approaches to supported decision-making might be more or less successful, depending on the narrative that the participant most identified with. They noted that clinicians may need to fill a variety of roles:

> To facilitate SDM, psychiatrists, other mental health clinicians (of all disciplines), GPs and other health professionals may need to act in a variety of roles: as facilitators (including trusting their patient to self-manage where appropriate and facilitating self-care and processes of recovery), as companions (getting to know their patients well and “being there” when needed), and as collaborators (providing options and information and, where possible a speedy resolution).[164]

Kokanovic et al’s study found that clinicians who had positive relationships with patients with mental health conditions were valued as supporters and identified as ‘enablers’ of supported decision-making.[165] Conversely, as noted below, where clinicians did not cultivate these types of supportive relationships, people with mental health conditions found it difficult to participate in decision-making about treatment.[166] For most people in this group, the role of family and peer support was also highly valued.[167] The importance of supporters having good interpersonal skills and strong relationships with the supported person were viewed as key to the success of supported decision-making in the mental health context.[168]

However, discrimination and stigma experienced in a hospital context by Victorian participants with mental health conditions resulted in them feeling ignored or judged less capable than others, and were major barriers to receiving good support for decision-making.[169] This finding was echoed by the participants who acted as family supporters to people with mental health conditions who had engaged with the mental health system in Victoria.[170] Family supporters also reported difficulties in being excluded from access to information or participation in decision-making which made supporting their loved ones at the end of involuntary treatment more difficult.[171] Conversely some supporters reported conflicting feelings about their supporter role. Stone et al, for example, highlighted that people in support or carer roles often had complicated relationships with the person they supported that could lead to their actions conflicting with what is expected of a good supporter (for example, being absent, prolonging detention, shifting into substitute decision-making).[172]

Studies have found that people with mental health conditions find retaining independence or control in their lives to be important, as did parents and members of their close circle.[173] In one study, both people with mental illness and their parents were supportive of supported decision-making but raised concerns about how it would operate during crisis mental health periods.[174]

The importance of educating clinicians who traditionally hold 'power' in relationships with people with mental health conditions has also been identified. It has been suggested that training the next generation of clinicians around the principles and concepts that move away from substitute decision-making towards supported decision-making will be crucial in embedding cultural and practical change in mental health services.[175] There has also been recognition of the potential role of technology in enabling supported decision-making in the mental health context.[176]

Outside the context of health care, limited research has been done on the role that supporters might play in assisting people with mental health conditions to manage their personal financial budgets. Hamilton et al found that in developing a person's own budget management skills, overlapping advocacy, substitute decision-making and support were needed. They also found a need for supporters to have access to information to act in this role.[177] Hale et al's study in Victoria considered a need for more support in decision-making around financial products when people with cognitive disabilities (including people with mental health conditions) were making financial decisions as consumers of these products. This need was perceived from the point of view of adults with cognitive disabilities, consumer advocates and financial organisations.[178]

5.3.3 Mental health (non-legal) supported decision-making initiatives

The literature reveals that many countries are grappling with how to implement supported decision-making in the context of existing mental health frameworks, and that fundamental concepts may need to be revisited for true domestic compliance with the CRPD requirements.[179]

The literature identifies several types of community programs[180] that seem to provide more than just decision-making support but have nevertheless been considered by commentators to fall within the ambit of supportive decision-making mechanisms and tools. Described below are the clubhouse model, WHO QualityRights, circles of support, peer support/advocacy and open dialogue.

Circles of support

Circles of support for people with intellectual disabilities have already been discussed above (at Section 5.1.3 *Circles of support*) and formalised 'microboard' models are discussed below (at Section Microboards *(and other incorporated networks)*. This group-based model of supported decision-making is used more commonly in relation to adults with intellectual disabilities but has also been identified as a method of support in the context of mental health.[181]

Some models that focus more broadly on supporting people with mental health conditions (beyond just decision-making) can include a wider circle of supporters. Support may include that provided by the wider community (for example, by service providers and non-government organisations etc), to be drawn upon as needed. One such model, known as Seher's 'Circle of Care' has been established in India. In that model Seher representatives facilitate access to supporters for people with mental health conditions included in the program.[182]

WHO QualityRights

This program of training, that contains an advanced module on supported decision-making, has broad application across cognitive disabilities. It does, however, have a strong focus on the mental health context. See above at Section 5.1.3 *WHO QualityRights.*

Clubhouse model

The clubhouse model is described as a ‘recovery-oriented environment for people living with mental health challenges’. This program of support for people with mental health conditions has been implemented globally and has a body of literature regarding its benefits in relation to different aspects of its program. However, as this model predates the CRPD, it has only recently been directly linked with the practice of supported decision-making. Corcoran et al suggest that supported decision-making is a ‘naturally occurring aspect’ of this model which fosters peer to peer and staff to member relationships in an inclusive environment where work tasks are incorporated each day and members are invited to contribute.[183]

Peer support/advocacy

This refers to the process where a person of equal standing with personal experience of mental health conditions provides support to a person in crisis and can act as an advocate.[184] They may also have a role in educating people they are supporting, for example in developing a psychiatric advance directive (see below at Section Psychiatric *advance directives/statements (PADs)*).[185] However, it has been noted that peer support workers can face challenges in providing consumers with support in decision-making.[186]

Open dialogue

This Finnish model involves people with mental health conditions engaging with family members, and others in their social network, to discuss important medical treatment options. This approach is recommended by the WHO and is described as a ‘flexible service for the treatment of psychosis in a community context not only with the potential to avoid coercive interventions and hospital admissions but also to improve the outcomes of psychosis’.[187] Decisions appear to be made ‘jointly’ under this model, but all are involved in the decision-making process.[188] Gooding notes that such a model offers ‘useful starting points to develop and implement workable measures of supported decision-making’.[189]

It is apparent from this brief overview that supported decision-making and general supports for persons with mental health conditions appear to be delivered hand in hand. Most of these programs consider supported decision-making in the context of a larger program, and many pre-date the introduction and widespread recognition of supported decision-making as a concept and distinct practice.

5.4 Dementia

People with dementia are more likely to be older individuals who experience a gradual decline in decision-making abilities along with their cognitive abilities. The changing nature of their decision-making capacities distinguishes them from groups whose capacity is more stable, such as people with intellectual disabilities. Also distinguishing them is that people with dementia are likely to have lived much of their lives making independent decisions and may have acquired professional or community responsibilities and/or amassed significant assets during their lifetime.[190] This is also likely to be the case for people with early onset dementia, other than those with Down Syndrome (among whom this condition is particularly prevalent). They may also have chosen to plan ahead, utilising legal mechanisms to ensure that their wishes are known, and that trusted friends or family have legal authority with respect to certain decisions.

While approximately seventy per cent of people with dementia live in the community, it is estimated that fifty four per cent of people living in residential aged care facilities have diagnosed dementia.[191] More recent statistics estimate that a further six per cent of residents have moderate to severe cognitive impairment from all causes (discussed below at Section Residential *aged care facilities*).[192] Some commentators have observed that older people with dementia may be less inclined towards adopting supported decision-making measures, partly because they may be more socially isolated, but also because they may prefer more familiar methods of appointing substitutes for decision-making.[193]

Unlike people with the cognitive impairments associated with other disabilities, people with dementia were not squarely considered as the target cohort for article 12 CRPD. People with dementia and their advocates were not included in negotiations and drafting of the CRPD.[194] They are also much more likely to be using services from aged care rather than disability systems. While dementias are now well accepted as being within the ambit of the CRPD, the literature in relation to supported decision-making in dementia is still emergent. The literature does, however, see promise in supported decision-making for people with dementia, but as with other groups of people with disabilities, no single model has been agreed upon for implementation.[195]

5.4.1 Conceptual complexities and controversies

A challenge identified in the literature for providing supported decision-making for people with dementia, is how to manage a person's past and present will and preferences, given that these may not align. This has similarities with the discussion above in relation to a person with ABI before and after the injury occurred (see above at Section Conceptual *complexities and controversies*). Wright describes dementia as a 'transformative event' because someone with dementia may experience 'radical and unanticipated changes in beliefs, preferences and values after its onset'.[196] The question of how much weight to give precedent autonomy as compared with expressed current wishes in the context of providing or implementing supported decision-making is unclear.

Where a person with dementia changes long held preferences or views as their condition advances, the question becomes – what is the support for? Donnelly suggests an approach that ‘rejects simple past/present distinctions’ instead describing what constitutes support in the following way:

> [S]upported decision-making is not about supporting a person to make the decisions/he would have made prior to dementia; nor is it about a simple hedonic response post dementia. Somehow, decision-making supports have to combine both the person’s past and their present; to recognise the ‘moral work done by memory and imagination’… yet simultaneously to respond to the person as a moral subject in his or her current state.[197]

Donnelly suggests that the complexity for supporters is in seeking to help make decisions that balance past and present selves, retaining the person’s identity while also accommodating and adjusting to changes that accompany the progression of dementia in that individual. A similar view is expressed by Sinclair et al who recognise that at a certain point, supporters may need to take a more active role in decision-making and strike a balance between ‘eliciting and acknowledging the person’s current will and preferences… while also respecting their previously established will and preference’.[198] In contrast, Wright sees supported decision-making’s role as being to support the *current* preferences and interests of the person with dementia – regardless of what their views were before.[199] In her view, apparent discord between past and present wishes (and past and present selves) ought to be resolved in favour of current wishes.[200]

As with other cognitive disability groups, the question of whether substitute decision-making for people with dementia – if underpinned by human rights principles such as respect for a person’s will and preference – can be compatible with the CRPD have arisen.[201]

5.4.2 What supported decision-making looks like for people with dementia

There has been a greater emphasis in this literature on how the expected cognitive decline experienced in dementia affects decision-making. As cognitive abilities are expected to decline, it has been observed that decision-making can take place autonomously, with support, jointly, and, ultimately via substitute decision-makers.[202] However, as noted by Sinclair et al, while a ‘spectrum’ of decision-making exists, support needs of individuals differ, and declines in decision-making ability are not necessarily linear in their progression.[203] ‘Independent’, ‘joint’, ‘supported’ and ‘substitute’ decision-making can also be intertwined.[204]

Research shows that adults with dementia wanted to feel that they were still central to decision-making, so that they could feel productive.[205] It was important for them that people around them supported this.[206] Research also emphasises the relational nature of decision-making by people with dementia:[207] ‘relationships are key in realising ‘inclusive citizenship’;[208] being included in everyday decision-making can bring a feeling of belonging, and adults spoke about finding a ‘negotiated position in their relationships’ and valued ‘interdependence’.[209] As with other cohorts, Keeling has suggested that supported decision-making requires the involvement of people who know the person with dementia well and that support should to be tailored to the communication needs of the individual.[210] A study by Sinclair et al that included interviews with people with dementia and their supporters/family/carers found that decision-making was described in a social context but many lacked access to social networks. Decision-making was also not considered a ‘single’ decision but a process over time, and while ‘maintaining involvement’ was a dominant theme, some adults with dementia preferred to withdraw from active decision-making over time.[211]

Research has found that strategies of supported decision-making for people with dementia include: allowing time,[212] and restricting the number of possible decisions or choices; clearly stating options, using aids to assist understanding, reducing the range of choices,[213] taking time to get to know the adult and developing trust,[214] and negotiating a compromise. Sinclair et al’s study found additional strategies used by family supporters included being patient, repeating information, breaking decisions down into stages, and communicating through multiple sensory modalities.[215] It has been suggested that a network of individuals around the person to invest time and effort is crucial, albeit increasingly rare.[216]

In the hospital setting, Miller et al’s study of persons with dementia found that when family caregivers perceive autonomy to be important to the adult, they can be an important advocate for continued involvement of the person with dementia in treatment decision-making or discharge planning.[217]

With respect to financial decisions, dynamics within a spousal relationship when one of them has dementia – could result in support being provided to maintain some participation in financial decisions. However, gender norms unrelated to cognitive capacity (ie where males were found to traditionally have made most financial decisions), were also found to influence whether adequate support was provided or accepted in financial decision-making.[218] For financial decision-making in residential aged care facilities, Tilse et al examined staff understanding of supported decision-making principles, finding that family and aged care staff often made decisions about the extent of an adult’s involvement in financial decision-making.[219] They found that complexities arose because capacity for daily shopping decisions may be different from capacity for long term decision-making about investments;[220] and assisting adults to remain involved in decision-making about money is challenging in aged care where dementias are prevalent and managers wish to avoid allegations against staff of financial misuse/abuse. A significant finding was that there was only limited support for adults who wanted to be involved in decision-making, and that frequently substitute decision-making was adopted as an easier option.[221] They noted that:

> [i]mproving practice will therefore need a commitment from residential care providers, funding and regulatory bodies, and adult protective services to challenge the environmental and attitudinal barriers to the involvement of older people.[222]

Research shows that it is normally anticipated that there will need to be a transition from supported decision-making – where the person with dementia makes their own decisions – to someone else making decisions on their behalf. However, where a substitute decision-maker continues to uphold the person’s ‘will and preference’ rather than be influenced by the ‘best interests’ of the person, then this is arguably still within the scope of supported decision-making (see above at Section Substitute *decision-making*). Sometimes this relinquishment of decision-making was at the wishes of the person with dementia but could also be initiated by family members who considered cognitive decline had reached a point where supported decision-making was ‘impossible’ or were concerned about an individual’s safety.[223] Bosco et al, similarly identify different factors that can lead to substitute decision-making (which they term ‘pseudo decision-making’). While sometimes this may be initiated by the person with dementia, it can also come about due to power imbalances in carer relationships, lack of accommodation or the time necessary for decision-making by the person with dementia or be due to organisational policies.[224] Strickland et al recommend that as a consequence of this transition, there should be ‘opportunities to renegotiate autonomy at times where there are significant changes in health or context’.[225] Where people with dementia do not want support to make decisions, and instead want others to step in and make decisions for them,[226] there is still a need to ensure that any substitute decision-maker is guided by the will and preferences of the person rather than ‘best interests’ in making decisions on their behalf.

A number of barriers to successful supported decision-making have been identified in the literature. Below at Section Residential *aged care facilities*, we identify particular issues in relation to provision of supported decision-making in the aged care sector. Within family settings, Sinclair et al conducted interviews of people living with dementia and their families and identified perceived implementation issues including time constraints, burnout among carers, conflicts of interest with other family members, and financial constraints on options available.[227] The Canadian Centre for Elder Law found barriers to supported decision-making for people with dementia in relation to investment decisions centred on questions of who was responsible for the decision and if undue influence was present as well as privacy concerns by institutions in discussing a person with disability’s case with a supporter.[228]

Given the heightened vulnerability of older people with dementia, concerns about elder abuse are also a common feature of the literature. Difficulties have been identified in viewing supported decision-making as a panacea for addressing elder abuse. Carney concludes for example that addressing elder abuse in Australia calls for only ‘measured adjustments’ to the law, with the crux being service delivery and compliance by state and private institutions.[229] He highlights the need for time and a nuanced application of the ‘will and preferences’ concept in the context of dementia care where present wishes (preferences) may be different to past expression of ‘will’, and points to the need for other protections for people with dementia who are subject to undue influence or exploitation in the community (ie bank card misuse) or the subject of physical or chemical restraints in aged care.

While there may be a push for advance directives or similar documents to be put in place to enable people to ‘plan ahead’, issues remain with such tools in the context of supported decision-making. In relation to people with dementia, recent studies of advance directive prevalence in Australia also indicate many people with dementia have no advance care planning documentation in place, and there are low rates of self-completed directives.[230] Such low rates may indicate that some people with dementia may instead choose to rely on existing networks of informal relationships.[231]

5.4.3 Dementia (non-legal) supported decision-making initiatives

A number of dementia specific supported decision-making tools and mechanisms were identified in the literature that were aimed at addressing aspects of supported decision-making.

CODEMamb tool

This tool was developed to aid in assessing capacity and in particular determining optimal methods for person centred communication with persons with dementia (including non-verbal communication). The authors have validated this observation assessment tool among older adults with varying levels of cognitive impairment and claim that it can 'differentiate between content-related and relationship aspects of nonverbal communication behavior'.[232] This is considered useful in that it can inform the tailoring of supported decision-making strategies, to best suit the needs of people with different types of cognitive impairment or dementia. While this assessment method has been tested in a clinic context, it is yet to be seen whether it is feasible and effective in the context of practical support for decision-making by supporters of varying levels of qualification.

ENSURE project

This project developed tools to enhance informed consent processes in the context of participation in dementia research. The study was premised on the idea that a deficit approach is usually taken to assessing capacity for people with dementia instead of an approach that focuses on remaining abilities and enhancing then. The study was part of the transnational ENSURE project (Enhancing the informed Consent Process: Supported decision-making and capacity assessment in clinical dementia research). Eight tools were defined and implemented as part of the ENSURE project. The authors found that dementia researchers were willing to use the tools, but as yet there is limited evidence on their effectiveness in practice.[233]

Talking Mats™

This is a non-legal supported decision-making mechanism consisting of 'a picture based framework designed to help people who have cognitive or communication difficulties expressing themselves'.[234] It was initially developed for work with people with intellectual disabilities to support communication for any purpose or context. Murphy and Oliver conducted a trial of using Talking Mats™ in decision-making by and with adults with dementia. While their article is positioned in a human rights framework it does not expressly frame Talking Mats™ as a tool for 'supported decision-making'. They conclude that Talking Mats™ are effective especially because: they increase feelings of involvement, help the adults see what they could still do (rather than focusing on deficits); and helped the adults be aware of what their family were doing for them (ie the trial involved family carers).[235] In other contexts (ie Parkinson's disease) Talking Mats™ have been useful in 'shared' negotiating between couples and help adults participate in decision-making as required by the CRPD.[236] An implementation trial of Talking Mats is currently underway in the Australian home aged care context, to determine whether this approach is feasible for aged care providers to deliver in practice.

PRODECIDE

This German education program was designed for legal representatives who can be appointed to support people who are ‘no longer able to handle their own affairs’ but in circumstances where there is no restriction of legal capacity for the adult.[237] When appointed for health matters, legal representatives need to have a certain level of knowledge of medical/health procedures to support adults to make decisions. For adults with dementia, interventions including PEG feeding, physical restraints and antipsychotic drugs may be used. The PRODECIDE education program was used to educate representatives on these issues. The publication of the protocol for a randomised trial in 2017 indicates that an evaluation is underway.[238]

WHO QualityRights

This program of training, that contains an advanced module on supported decision-making, which is also applicable in the context of people experiencing dementia, has been described above at Section 5.1.3 *WHO QualityRights.*

CDPC Supported decision-making for people with dementia training

In Australia, researchers from the Cognitive Decline Partnership Centre designed an introductory training package titled ‘An Introduction to Supported Decision-Making for aged care providers’. This six-hour training package covers the human rights principles underpinning supported decision-making, lived experiences of people with dementia and their family members regarding supported decision-making, and a series of case-based exercises to promote a problem-solving approach to providing supported decision-making. The training package was piloted during 2019, and while this pilot data is not published as yet, preliminary evaluation data (n=108) indicated a positive view of the content and delivery of the training package (95 per cent agreed or strongly agreed ‘the material presented was relevant to my role’, 97 per cent agreed or strongly agreed ‘my awareness and understanding of supported decision-making has increased’), indicating a strong appetite for training in this area.

6. Communities in Australia

6.1 First Nations People

There appears to be little published research specifically addressing supported decision-making in the context of First Nations peoples. Clapton et al identify issues affecting capacity to deliver supported decision-making for First Nations peoples, including: intergenerational trauma; mistrust and suspicion of existing guardianship and administration systems; 'a lack of cultural awareness and understanding of Indigenous people's history, kinship responsibilities, cultural values and beliefs and ways of working' in state-led support systems; a cultural incongruence between Indigenous and Western worldviews in relation to individualism, collectivism and decision-making; barriers to accessing support services, such as language barriers, stigma and shame; and, cultural bias in systems designed to assess cognitive (and decision-making) capacity.[239] Similar themes are addressed in literature on end of life decisions by Indigenous peoples in New Zealand, Canada and the United States.[240]

The evaluation report of a supported decision-making trial in NSW (see below at Section *Supported decision-making pilots – with published results and/or evaluations*) mentions that two out of the 33 decision-makers identified as First Nations people. However, no analysis was provided as to whether or how supports were tailored for these two individuals or if their outcomes were different from others.[241] Below we refer to limited research on First Nations peoples and access to the NDIS (see below at Section NDIS). The 'Tree of Life' practice guide for supporting people to make decisions about personal safety and well-being, was based on research conducted with workers at the Sydney Regional Aboriginal Corporation and the Multicultural Disability Advocacy Association of NSW (see Section 9.2 above). However, the research itself has not been published.

This lack of published research is significant as there are higher rates of disability in First Nations communities as compared with other Australian communities and:

> '…the nature of disability as experienced by this group is predominantly (but not only) related to mild to borderline intellectual disability, very often in combination with a range of mental health issues. Moreover, many people within this population group have a high incidence of acquired brain injury. The combination of these issues impacts significantly upon the person's daily functioning and can result in compounding social disadvantage and complex service-related needs.'[242]

While not referring specifically to support for decision-making, Baldry et al advocate for culturally appropriate 'person centred support' for First Nations peoples with mental and cognitive disabilities.[243] The need for culturally appropriate information and training for government agencies interacting with First Nations people who experience disability is recognised by statutory bodies, such as the Office of the Public Advocate (Vic), which has published guidance for its staff on interacting with First Nations clients.[244] Similar guidance may be appropriate in relation to implementing supported decision-making in various contexts.

6.2 Culturally and linguistically diverse people with disabilities

There is an absence of analysis about the practice of supported decision-making amongst culturally and linguistically diverse populations. As referred to above in 6.1, research on supported decision-making was conducted with the Multicultural Disability Advocacy Association of NSW, resulting in a practice guide. In other cases, while it is likely that people from different backgrounds and cultures participated in research, to date the research findings have not focussed on the impact of participants' cultural or ethnic background on conclusions drawn about supported decision-making. While some published studies on decision-making and people with intellectual disabilities indicated that they included participants from culturally and linguistically diverse backgrounds, systematic, structured research on how decision-making supports may need to be tailored for diverse cultures is lacking. In one study of aged care residents, a comment was made that for refugees who had arrived in Australia with few possessions, access to cash was a strong preference in their financial decision-making.[245] Zannettino et al describe the literature as acknowledging that older people from culturally and linguistically diverse backgrounds are 'particularly susceptible to financial abuse by their family members'.[246] They further write that the nature of this vulnerability is underexplored, but is exacerbated by cultural expectations around family privacy and also by the adults' dependency on others for 'translation of financial transactions, and services.'[247]

The Canadian Centre for Elder Law, in researching barriers to supported decision-making in investment decisions, noted that cultural background could lead financial advisors to misinterpret behaviours and communications.[248] Sinclair et al's research on the views of people with dementia and their family members on supported decision-making, noted the participants' countries of birth – with five out of twenty-nine adults living with dementia and eleven out of thirty-two of their family members born overseas.[249] They mention that one woman 'had pressure culturally' to nominate her son as an enduring power of attorney rather than her daughter, but no further analysis of cultural issues is explored.[250] Sinclair et al recognise the need to 'undertake broader consultation with diverse community groups…' and 'culturally-specific service provider organisations' on supported decision-making for people with dementia.[251]

In 2021 Vanegas et al published a scoping review of literature on cultural differences in decision-making practices by, with and for youth with intellectual disabilities transitioning to adulthood. The authors found literature indicating differences in decision making between those cultures that prioritised individuality, as opposed to those that prioritised family and community. That review concluded that the impact of cultural diversity on decision making and people with intellectual disabilities is under-investigated, and that further research was needed so as to develop effective supported decision-making.[252]

6.3 Gender, sexuality and people who identify as LGBTIQ

A gap in the literature exists on supported decision-making and those who identify as LGBTIQ. Only one unpublished paper on guardianship and LBTIQ people was found that also mentioned supported decision-making as a potentially preferable alternative to ensure that consideration of the adult's identity was central to decision-making.[253] This extremely low yield is consistent with findings that there has been a lack of research generally on issues affecting people with intellectual disabilities who identify as LGBTIQ,[254] and the little there is suggests disability service systems demonstrate little capacity to adjust support to the needs of this group.

In relation to gender, the CRPD Committee notes that 'Certain jurisdictions also have higher rates of imposing substitute decision-makers on women than on men' and yet the intersection of gender with supported decision-making appears to be relatively under explored.[255] There have been some limited findings on how gender affects supported decision-making in the case of heterosexual couples where one person is supporting the other experiencing dementia.[256] Commentary on domestic violence and elder abuse[257] against people with disability points out that women are disproportionately affected[258] and that relationships of so-called 'support' may shroud situations of abuse. These observations and analyses raise broader issues of what safeguards should be developed for supported decision-making (see below at Section Safeguards).[259] It should also be noted that there is a large body of literature on reproductive health issues experienced by women with disabilities. While some of this relates to decision-making by women with cognitive disabilities, it is more widely situated in the guardianship, health and bioethics literatures.[260] The extent to which supported decision-making is able to address such gendered issues is unknown. Whether gender influences should be taken into account in support for decision-making requires further research.

Research does show that one area where supported decision-making can be lacking are decisions relating to sexuality and intimate relations. Harding and Tascioglu's research showed that in England attitudinal barriers existed among professionals who would otherwise be in a position to support a person with a disability in relation to intimate relationship decisions.[261] A small study focusing on the experience of pregnant women with intellectual disabilities showed that the quality of relationships held by the women with their 'support network' was crucial in facilitating decision-making in relation to pregnancies.[262] McCarthy et al, in a study interviewing adults with cognitive disability on their 'loving relationships' identified that lack of autonomy in decision-making was one constraining factor.[263]

7. Service system contexts of supported decision-making

The significance of the context in which supported decision making is implemented is a common feature in the literature across the four groups of people with intellectual disabilities, ABI, mental health conditions and dementia. Service system contexts inevitably overlap (for example, health care delivered in a residential aged care facility) and we are also starting to see the issues involved in transitioning between different service system contexts and the significant decisions that need to be made in doing so. For example, decisions to transition from the NDIS into residential aged care facilities, with consequent loss of funding. While we see the emergence of research targeting particular types of decisions (for example, will making[264] and voluntary assisted dying[265]) we see little evidence in Australia that supported decision-making is being provided for these types of significant decisions involving transitions between service systems, despite it seeming crucial.

Outside of service systems, spheres of life in civil society – that is, families, communities and other networks – may be relied upon by people with disabilities to provide supported decision-making informally. For some individuals there may be significant engagement with service systems across their lives, while for others interactions may be brief, episodic or largely absent. However, here we briefly discuss significant service domains with which people with disabilities are likely to interact.

7.1 NDIS

The NDIS is founded on a philosophy of 'choice and control', allowing participants to choose and design individualised packages of supports and services. However, commentators have pointed out that adults with cognitive disabilities risk being disadvantaged under such a model, with its emphasis on individual contracts and decision-making.[266] In this context, advocates have stressed the importance of providing participants with support for decision-making.[267]

However, the NDIS legislation does not incorporate any system of supported decision-making other than nominee provisions,[268] nor does it allow funding of supported decision-making in a participant's package.[269] Soon after its formation, the NDIA Intellectual Disability Reference Group a sub group of the Independent Advisory Council raised the importance of people with cognitive disability of having access to supported decision-making with the Commonwealth Government.[270]

In 2015 the Commonwealth Department of Human Services began funding advocacy services |to pilot provision of supported decision-making to potential participants, without informal supports, to access the NDIS.[271] While this funding has been welcomed, this program runs the risk of confounding individual advocacy with supported decision-making practice. A 2019 review of the NDIS legislation identified supported decision making as an outstanding policy matter, and recommended for inclusion as an item in the Disability Reform Council's forward work program, "the role of nominees, guardians and supported-decision making under the NDIS, including the intersection between the NDIS and state and territory guardianship legislation".[272] In response to this recommendation, in 2021 the NDIA released a consultation paper on supports for decision-making,[273] and a 'Companion Paper: Supporting you to make your own decisions' which affirmed the NDIA's commitment to uphold the human rights of people with cognitive disability.[274] At the time of writing, the consultation is still in progress.

There are two key steps to gaining access to NDIS supports. First, the participant must satisfy the eligibility requirements. Once deemed eligible, the second step involves a planning meeting with an NDIA officer to develop a plan for ‘reasonable and necessary’ supports. The NDIS legislation contains provision for plan ‘nominees’ so that when a participant has decision-making challenges, they can either choose to appoint a plan nominee to make decisions for them or the NDIA can appoint one for them.[275] A nominee is therefore a type of substitute decision-maker.[276] In practice, relatively few nominees have been appointed,[277] and in many cases guardians have been appointed instead, leading to apparent increases in formal substitute decision-making arrangements.[278]

There has been no empirical research focused directly on supported decision-making in the NDIS. There has however been some broader research on the conduct and outcome of planning meetings. Perry et al undertook a study of NDIS planning experiences for people with intellectual disabilities and found that an effective process was key to participants having greater choice and control. Findings included that informal support at the planning meeting was crucial for decision-making,[279] and that lack of sufficient information beforehand, could impede choice.[280] Of concern was that planners would sometimes direct conversations to the support person, thereby marginalising the participants.[281] Lloyd et al report perceptions of parents that NDIS planners lacked ‘specific knowledge of participants with intellectual disabilities, lacking sensitivity towards family situations and a positive vision for the adult’s future.’[282]

Other research found that: people with complex needs often do not have informal support for planning, and confirmed that planners themselves do not always have the skills to provide the relational support required.[283] Collings et al found that for participants with intellectual disabilities a relationship of trust between the participant and the planner was key and that people without informal support networks would require substantial assistance from a skilled planner.[284] This suggests that those without pre-existing support structures are not likely to be armed to self-advocate for the best funding support and may consequently miss out on funding that an equivalent person with good supports for decision-making in place may receive. This raises issues of equity between those who have the benefit of pre-existing supports and those who lack supports, particularly in light of the fact that the NDIS will not fund support for decision-making.

Once a plan is settled, responsibility for its implementation, securing services and seeking review if circumstances change, rest with participants. In the case of people with cognitive disabilities, this means that they are likely to continue to need supported decision-making. There is little research about these parts of the NDIS journey, but some early reports suggested for some participants the absence of good support led to delays in accessing services and underspent budgets.[285]

Laragy et al reviewed evaluations of NDIS trial sites to find that: ‘NDIS participants with a mental/psychosocial disability gave the lowest rating to having choice and control’.[286] Higgins and Nunan made a narrow finding that peer education for people experiencing mental illness (that is, as part of the recovery model) ‘is vital in supporting people with a lived experience of mental illness to exercise choice and control under the NDIS’.[287] Spivakovsky notes the high proportion of people with intellectual disabilities in the criminal justice system and that this double marginalisation adversely impacted on the effectiveness of the planning process and access to NDIS support.[288]

There has been some research on NDIS accessibility for First Nations people, but not on supported decision-making.[289] Gordon et al describe how the effects of colonisation have left First Nations people multiply marginalised, so that they are at a significant disadvantage when it comes to interacting with the bureaucracy and obtaining services.[290] They point out that colonisation has been responsible for causing disability amongst First Nations people, but also for containing them within a culture of charity and welfare.[291] These disadvantages are likely to be magnified under the NDIS's free market approach, as no incentives are provided to provide 'culturally safe or rural and remote care'.[292]

Dew et al point out generally that First Nations people who get through to the planning stage require planners who are sensitive to cultural values.[293] Other literature points out communication difficulties, not just because some First Nations people speak English as a second language but because they do not conceptualise 'disability' in the same way as their colonisers.[294] In the absence of specific research, it is not possible to say how supported decision-making in the NDIS do or would function for First Nations people, except that such practice would need to be led by First Nations people and organisations, to ensure cultural capability.[295]

In the case of participants from culturally and linguistically diverse backgrounds, despite their high rate of disability (including intellectual disabilities) Soldatic et al report that 'they are four times less likely to access government-funded disability supports'.[296] As indicated above, there has been no research specifically focusing on culturally and linguistically diverse communities and support for decision-making – either in relation to the NDIS or more broadly and is a significant gap in the literature.

7.2 Residential aged care facilities

In Australian residential aged care facilities over 50 per cent of residents have dementia.[297] Without access supported decision-making, these people risk having decisions imposed on them by others on a range of issues from everyday routines to major health interventions.

Many issues arising in residential aged care are similar to those experienced in other types of supported accommodation. The transience of staff and resourcing constraints impede opportunities for developing trusting relationships and obtaining quality supported decision-making.[298] The issue of staff lacking time to engage in supported decision-making was also apparent along with the recognition that provision of good supported decision-making is 'resource intensive' and 'difficult to facilitate'.[299] One realm of decision-making where this has been recognised is in relation to residents making decisions regarding intimate or sexual relationships with others.[300]

Sector wide, there is more reliance on substitute decision-making mechanisms to manage institutional risk[301] and a tendency to prioritise 'protection' over autonomy, particularly for adults with dementia.[302] Studies have shown that attitudes and practice of staff and organisations will need to change. For example, Sinclair et al undertook a study of aged care organisational policies (from 7 Australian aged care organisations) with accompanying staff interviews, to determine whether and to what extent they aligned with the decision-making principles recommended by the ALRC.[303] The authors devised 9 domains against which to audit such policies. There were differing levels of compliance with and implementation of ALRC decision-making principles which seek to promote and implement supported decision-making. Findings from interviews with management level staff on challenges to implementation in the aged care context included: concerns about safety and risk versus duty of care; perceptions that some workers needed very explicit/direct instructions (which were lacking), existing cultures were hard to shift, and frontline workers were not usually involved in policy development.[304] The authors concluded there were significant gaps and suggested that high level policy guidance from regulators could assist in shifting policy and practice.[305] Such guidelines have been developed and have been referenced by the Aged Care Quality and Safety Commission under the Aged Care Quality Standard in relation to consumer dignity and choice.[306]

Views were also expressed that undue influence or abuse in decision-making could occur but workers felt this could be diminished by getting to know residents well, taking a multi-disciplinary approach and responding to resident cues.[307] Some of these findings are similarly reflected in other countries, albeit in the context of different legal frameworks. For example, in Sweden, adults with impaired capacity have the right to make their own decisions on care services, so balancing this right against potential harms is left to practice, which creates dilemmas for professionals and families.[308] Larsson et al's systemic review of empirical research found that when adults with dementia transition to residential aged care they can be excluded, or have 'prior preferences … taken into account', or current preferences are respected.[309] It concluded that while legal changes have increased awareness of rights, this was not reflected by changes in practice, where exclusion of the adult from decisions still occurs.[310]

As with other sectors, there is a recognised need for staff within residential aged care facilities to be trained in providing supported decision-making to people with dementia.[311] However, this faces challenges; high staff turnover means significant resources have to be committed to training in basic competencies, which means that non-mandated training can fall by the wayside. While the Cognitive Decline Partnership Centre has developed generic training for aged care staff on supported decision-making (discussed above at Section Dementia *(non-legal) supported decision-making initiatives*), it seems likely that unless such training is linked to standards to which organisations must comply, this may become another training option only accessed by motivated staff members.

7.3 Health care

The health system is likely to be engaged with by all people with disabilities at some point, to varying degrees. What role do health care professionals play in supporting decision-making and what is known about it in the health care sector?

Health care professionals are likely to be crucial in implementing supported decision-making for health care decisions. They are often asked to assess decision-making capacity of patients[312] and can therefore act as a gatekeeper to a person being formally recognised as unable to make some decisions. They are also well positioned to identify how additional communication aids or interventions might help a person with a disability to retain and exercise their autonomy in decision-making. They will also need to recognise other people who are providing support to individuals and adjust their behaviour accordingly – such as being prepared to have them present during consultations, sharing medical information about the individual with them, discussing options with the supporter(s) so they can talk through them again with an individual at a later time. Wright notes, however, that there is a lack of clarity around responsibilities of health care professionals' responsibilities in this context, for example, what role should they have in detecting undue influence?[313]

Sinclair et al found in their small qualitative study with some health care professionals that a range of approaches to supported decision-making were used. Some approaches were more conducive to including other supporters into decision-making processes. One finding was that some considered there was a need to maintain 'objectivity' and 'professional distance' with some concerned about being held accountable, particularly for 'risky' decisions made by patients with dementia.[314] In those jurisdictions without formal recognition of supporters, supported decision-making may also be met with resistance in the face of concerns of breaching confidentiality and a 'fall back' on substitute decision-making authority may be expected. Donnelly et al's qualitative study of Irish health and social care professionals found, consistent with other literature, that knowing the patient and having the time to build a therapeutic relationship were 'critical enablers' of supported decision-making; however, this could be hard to establish in the acute care environment.[315]

In some cases health care professionals may also be called upon to act as a supporter for a person with a disability who is trying to make a health care decision.[316] While the concept of 'shared decision-making' – where a decision is made jointly between patients and health care professionals – is widely known in medicine, the same is not true for supported decision-making, despite there being significant overlap between the two.[317] There are two types of decisions where supported decision-making might be sought. The first, and more common, is direct support to make health care decisions. However, health care systems may not be set up to allow good supportive relationships to flourish between patients and health care professionals:

> Many studies, including one from Ireland, highlighted several contextual influences that mitigate against the provision of quality person-centred care in relation to [supported decision-making]. These include lack of time, competing clinical work, fragmented care services, inadequate professional collaboration and uncertainty in professional roles in relation to [supported decision-making].[318]

In addition, health care professionals may have to contend with colleagues or family members of the patient pushing for a more paternalistic 'best interests' approach to decision-making. This was evident in Donnely et al's study of older patients in acute care settings and seen as a barrier to implementing supported decision-making.[319] The need to consider the physical environment, for example, a quiet space for conversations away from noisy wards, was also identified as an enabler of health care professionals providing supported decision-making for patients. [320]

Another situation in which support for decision-making may be sought is in relation to advance planning of treatment choices. In some jurisdictions a medical practitioner is required to be involved and must sign such documents, perhaps increasing the chance that they will be asked to provide supported decision-making.[321] Support is likely to be needed to navigate, articulate and execute advance directives, particularly where specific health care decisions need to be incorporated. This process may be used in the mental health context where people with mental health conditions wish to plan ahead to avert another crisis episode or make their wishes regarding treatment known, or more generally where people are anticipating medical treatment decisions will arise.

A recurring theme in the literature is the need for leadership and cultural change, as well as targeted training if supported decision-making is to be understood and practice changes successfully implemented in the health care context.[322] Some of this has started to occur in some countries, with the Irish PADMACs study one such initiative focusing on decision-making in acute settings by older patients with cognitive impairments.[323] The need for education has been particularly recognised in the context of the mental health system.[324] Some commentators have suggested that health care professionals' knowledge of shared decision-making practices can be drawn upon to help educate them about supported decision-making.[325]

Health care professionals may also be instrumental in encouraging supported decision-making practice by advising those who end up acting as substitute decision-makers for health care decisions for others (see below at Section Health *care*). Often those who act in these substitute decision-maker roles will be unaware of the decision-making principles that they are legally expected to follow. In some jurisdictions these principles squarely place the individual patient's (as opposed to the substitute decision-maker's) wishes as relevant to the decision, and in some jurisdictions may require that supported decision-making be attempted before substitute decisions are made (see below at Section Legislative *principles recognising a supported decision-making approach*). Health care professionals may be best placed to educate substitute decision-makers about their obligations to consider these principles in the decision-making process. However, this may be expecting too much. Evidence in England showed that health services were failing to comply with the requirements of its *Mental Capacity Act 2005* (England and Wales) when making health care decisions,[326] and Australian studies in other areas of health care decision-making demonstrate low levels of legal knowledge by professionals.[327]

7.4 Supported accommodation

People with all types of disabilities may live in forms of supported accommodation. Supporter relationships in supported accommodation – especially in group settings – can be unequal, with uneven power relations between staff and residents. Residents in smaller, community-based supported accommodation settings are better supported to make everyday decisions, than their counterparts in larger congregate residential settings.[328] However, even in smaller community-based settings there is significant variation in the quality of support, and in some services decisions about everyday activities are often made by staff, reflecting their own preferences, or what they perceived as beneficial for the whole group of residents, rather than any individual resident's will and preferences.[329] The research above (at Section Who *provides support*) shows that residents in supported accommodation may seek supported decision-making from paid staff or professionals at these services. This may be in conjunction with support that they obtain from other people outside the service – such as family, friends, service coordinators or case managers – or may be the only source of supported decision-making they seek in day to day living. Supported decision-making in this context raises a number of issues for consideration.

First, are the problems of high staff turnover and maintaining continuity of care which affects the quality of support for decision-making provided by paid staff or professionals:[330]

> The shift to individualised funding under the NDIS was promoted as having potential to deliver greater 'choice and control' in allowing participants to move their funding from one service to another. However, this shift has also led to more precarious labour for disability support staff…, undermining their capacity to get to know service users well, which is an essential condition for successful support for decision-making.[331]

Second, are the low staff ratios or chronic understaffing in some supported accommodation that may mean staff do not have the time to provide support for decision-making as they are already stretched thin in their roles.[332]

Third are the tensions between respecting an individual's autonomy while also owing them a duty of care – often interpreted informally by staff on a day to day basis – that may lead staff to err on the side of protection and not provide the support needed to make decisions.[333] Finally, is the recognised need, identified across all service system contexts, for education and training of the staff who may be called upon to act as supporters – whether acting informally or formally appointed.

7.5 Criminal justice system

People with cognitive and psychosocial disability are over-represented in the criminal justice system and experience significant disadvantage in the processes leading to imprisonment, as well as greater exposure to harm within criminal justice settings.[334] The criminal law in Australia provides what have always been considered two 'protections' for adults with impaired capacity. The first is that a person may raise as a defence that they were of 'unsound' mind at the time of committing an offence. The second is that if a person is found 'unfit to plead' by way of impaired capacity, then they will not stand trial for the offence.[335] On one interpretation of article 12 CRPD, this differential treatment of adults with cognitive disabilities is said to amount to unlawful discrimination,[336] but the issues from a criminal law perspective are complex.[337] Particular human rights concerns have been raised about adults who have been found unfit to plead, only to find themselves held in a forensic disability or mental health service for indefinite periods.[338]

In this context, there has been some consideration about what supported decision-making may look like for adults with cognitive disabilities as potential defendants in the criminal justice system. Gooding et al conducted a pilot program to provide non-legal supports to people with cognitive disabilities, so that they could avoid an ‘unfit to plead’ determination and have the right to participate in a criminal trial. Four workers were trained to provide support for adults by way of communication assistance, procedural accommodations and relationship building between legal centres and community services.[339] The program was successful in that it ‘appeared to improve participation and outcomes for accused persons’.[340]

Gooding et al describe how supported decision-making was but one accessibility and accommodation measure provided within a broader program of supports.[341] Dhanda advocates for supported decision-making for people with cognitive disabilities in the criminal justice system and acknowledges that this requires a total ‘redesign’ of that system.[342] The Office of the Public Advocate (Vic) has similarly recommended that governments provide broad support (not just for decision-making) for adults with cognitive disabilities to ‘understand and participate in criminal justice processes, including procedures in police stations and in courts’.[343] We note that in the criminal justice process ‘decision-making’ would not appear to be the crucial or central focus for supports. The program undertaken by Gooding et al and the recommendation of the Office of the Public Advocate suggest that support is required not so much for decision-making, but for ‘legal capacity’ in a broader sense of meaning the right to be recognised as a person before the law.[344]

7.6 Voting

Article 29 of the CRPD provides that people with disabilities have a right to participate in political life including a right to vote. The effect of article 12 of the CRPD is that their legal capacity to vote must be recognised. In many countries the appointment of a guardian may mean that an adult no longer has a right or opportunity to vote.[345] While this is not the case in Australia, the *Commonwealth Electoral Act 1918* (Cth) nevertheless provides that: a person of ‘unsound mind’ who is ‘incapable of understanding the nature and significance of enrolment or voting’ is not entitled to vote.[346] This provision has been widely criticised by disability advocates, leading to recommendations for amendment together with research on practical barriers to voting for adults with cognitive disabilities.

The ALRC Report recommended that electoral legislation be amended to repeal the ‘unsound mind’ carve-out described above and provide instead that it would be a ‘valid and sufficient reason’ for failing to vote if an adult does not have functional decision-making capacity. The effect of this would be that an adult with cognitive disability would have the right to vote; but would not be penalised for failing to do so, if they did not have the capacity to understand, retain or weigh the relevant information or did not have the capacity to communicate their vote.[347] The ALRC Report further recommended that returning officers should be provided with training on the National Decision-Making Principles, and that an adult may be permitted to choose someone to assist them with voting.[348] Bigby et al conducted research on barriers to and facilitators of voting in Australia, with recommendations including that electoral commissions and non-government bodies explore strategies to produce and disseminate accessible information about public affairs.[349] However, little research has been done on how supported decision-making may assist people with disabilities to vote.

7.7 Research

Supported decision-making in the context of consent for participating in research, is an emerging area.[350] The use of supported decision-making to involve people with disabilities as research participants, but also as research partners, is largely unexplored. People with disabilities, particularly people with high support needs, are often excluded from research (including medical research) and this can have negative consequences, ultimately reducing the number of options for some groups of people. As noted by Bierer et al, in the clinical setting, this can result in serious inequities:

> [T]here is evidence of disproportionate exclusion of people with cognitive disabilities from participation in clinical research… The lack of inclusion has acutely reduced opportunities for people with disabilities to benefit from clinical research, diminished the potential representativeness and generalizability of studies, and left gaps in the clinical evidence base often for the most seriously disabled.[351]

Supported decision-making is viewed as one way to increase the involvement of people with disabilities in research.[352] The current National Statement on Ethical Conduct in Human Research, which guides Australian researchers, provides guidance on that information about research should be presented in a way that supports a person's their participation. This includes considering methods of communication, and taking into account visual, hearing or communication impairments, as well as age and cultural background.[353] The National Statement also alludes to supported decision-making in discussing consent processes:

> In the consent process, researchers should wherever possible invite potential participants to discuss their participation with *someone who is able to support them in making their decision*. Where potential participants are especially vulnerable or powerless, consideration should be given to the appointment of a participant advocate (emphasis added).[354]

However, this is in the context of vulnerability of people in 'dependent or unequal relationships' and a similar statement is not included in the discussion of consent in the chapter on 'People with a cognitive impairment, an intellectual disability, or a mental illness'. This is a notable omission. More explicit mention of supported decision-making in national ethical research guidelines would be beneficial in providing greater guidance, particularly to researchers and human research ethics committees.

Whether supported decision-making in this context might be implemented through use of advance research directives, or the ability to appoint research 'proxy' decision-makers, has begun to be considered.[355] However, the current legal frameworks in Australia remain fragmented between States and Territories.[356]

Barriers to applying supported decision-making currently exist in this area, because the emphasis has been on protecting vulnerable populations from exploitation. Research is subject to governance by human research ethics committees constituted predominantly by scientists, lawyers and lay people. Research institutions are more accustomed to excluding people with disabilities, or else relying on a substitute decision-maker's legal authority to include a person in research.[357] There is a need to train and educate researchers, as well as members of human research ethics committees, before supported decision-making will be successfully implemented in the research context. We note that the current ENSURE project (Enhancing the informed consent process: Supported decision-making and capacity assessment in clinical dementia research) (discussed above at Section *Dementia (non-legal) supported decision-making initiatives*) has developed tools to enhance informed consent processes in the context of participation in dementia research. To date they have found researchers open to using the tools developed and this emphasises, 'the importance of developing training courses in the field'.[358]

8. Legal mechanisms of supported decision-making

This part of the review describes the legal mechanisms introduced into law domestically and overseas to implement aspects of supported decision-making. The first section describes Australia's current guardianship legal frameworks as compared with other countries and addresses the issue of the practice of supported decision-making when a substitute decision-maker is formally appointed for a person with disability. (In referring to substitute decision-making frameworks and guardianship legislation, we are referring to the legislation that governs decision-making for and on behalf of adults that may consist of laws relating to guardianship and administration, enduring powers of attorney, medical decision-making, advance directives etc. This is distinct from mental health legal frameworks). The second section identifies general legal mechanisms that exist globally may be used across all disabilities. This is followed by reforms in mental health legal frameworks that purport to incorporate aspects of supported decision-making. This part concludes with a critique of some of the legal reforms.

Spurred by the creation of the CRPD, law reform commissions reviewing guardianship and substitute decision-making legislation in Australia have strongly recommended incorporating various legally recognised forms of supported decision-making,[359] as have law reform agencies worldwide.[360] Indeed, the UN Special Rapporteur on Rights of Persons with Disabilities reported that at least 32 countries had undertaken or were implementing legal reforms as a consequence of the CRPD.[361] Relatively recent legal reform has introduced frameworks for various forms of supported decision-making in States and Territories in Australia (eg Victoria, Queensland), eighteen States (and the District of Columbia) in the US,[362] Ireland, Peru, Israel,[363] Argentina[364] and Scotland.[365]

The benefits of legally enshrining aspects of supported decision-making are various:

providing an alternative to rights restricting substitute decision-making;

preventing the removal of decision-making rights for people with disabilities;

the political and societal value in formally recognising that people with disability are entitled to supports and to having their decision-making autonomy respected;

- providing a catalyst to shift ingrained practice and attitudes within professions or service delivery contexts. For example, while recognising the difficulties in accommodating the 'hard' cases, Glen argues that the 'expressive' value of law is important in framing and changing 'social perceptions and actions' and thus the insistence on 'will and preferences' in all cases is important.[366]
- providing certainty for third parties.[367] Some third parties, such as financial institutions or people who wish to enter into contracts, may otherwise refuse to recognise a supporter's actions in attempting to support decision-making (by, for example, accessing information on their behalf). This may be due to fears of breaching privacy requirements or fears of a supporter exerting undue influence or coercion.[368]
- clarifying the legal standing of a supporter of a person with a disability[369] as without legislation, informal decision-making is considered 'unprotected in a legal sense'.[370]

- providing opportunities for implementing legal safeguards – something that informal support for decision-making practices lack, which can leave the supported person open to risks of abuse (see below at Section Safeguards in legislation).[371]

Before reviewing supported decision-making legal mechanisms, it is worth noting how substitute decision-making schemes have generally been viewed in opposition to supported decision-making and how Australia's current substitute decision-making frameworks significantly differ from legal frameworks in other jurisdictions.

8.1 Australian substitute decision-making frameworks and supported decision-making

As noted above, the CRPD committee has stated that many substitute decision-making schemes are non-compliant with the CRPD and should be replaced with supported decision-making schemes.[372] The literature shows that many advocates and scholars agree with this approach, but particularly those in the US.[373] It is worth recognising however that, unlike in Australia and some other jurisdictions (eg UK),[374] the dominant model of guardianship in the US (and some Eastern European countries) is for the appointment of 'plenary' guardians. A 'plenary' guardian has unlimited authority to make decisions in all domains of a person's life – including for example, health, accommodation, education, services, social arrangements and finance. Moreover, appointments in the US are typically for an indefinite time period and applications to the courts for revocation are costly.[375]

While Australian guardianship regimes still rely on capacity based assessments to impose substitute decision-making, by way of contrast, since the 1980s most Australian states and territories have significantly reformed their systems so that they are more aligned (but by no means fully compliant with) with CRPD goals. Current safeguarding features typically include: time limited appointments; appointment limited to specified decisions (ie not plenary); decision-making principles emphasising a person's will and preferences; diminished resort to 'best interests' decision-making and accessible oversight by tribunals, not courts.[376] Many of these features of Australian systems have only recently been enacted in other jurisdictions.

As noted below, Australia's legislation continues to be reformed to align better with CRPD aims. Some jurisdictions have explicitly incorporated supported decision-making mechanisms into their frameworks to work in conjunction with existing substitute decision-making legal schemes.

This review has identified that supported decision-making can still be practised where a legally recognised substitute decision-maker is in place. This is particularly so in the Australian context where plenary substitute decision-making appointments are rare. Even where a substitute decision-maker is appointed, the narrow scope of those appointments mean that some decision-making rights will remain with the person with a disability and as identified below, supported decision-making often needs to be attempted prior to turning to substitute decision-making. The next section considers the situation of supported decision-making where a substitute decision-maker is in place.

8.2 Supported decision-making when a substitute decision-maker is in place

While substitute decision-making is often regarded as the antithesis of supported decision-making, as discussed above (at Section Australian *substitute decision-making frameworks and supported decision-making*), the Australian framework for substitute decision-making differs vastly in its operation from other countries.

While there is certainly room for improvement in many States and Territories substitute decision-making laws, the common features of adopting a least restrictive approach, time limited appointments and the additional incorporation of supported decision-making practices in some jurisdictions, mean that supported decision-making practices are not necessarily considered incompatible with Australian substitute decision-making legal frameworks.[377] As discussed below, in some States in Australia the legislation has adopted an approach that requires supported decision-making be attempted before any recourse to substitute decision-making, including by appointed substitute decision-makers.[378] This more nuanced legislative approach goes some way to recognising that support and substitute decision-making exist along a spectrum. Indeed, research has found that supporters naturally move between acting as a supporter into an informal substitute decision-making role depending on the situation.[379] However, the ability to formally appoint a substitute decision-maker for an individual will remain in Australia for the foreseeable future. As such, here we briefly discuss the relevance of supported decision-making when a substitute decision-maker is in place for an individual.

8.2.1 Tribunal appointed substitute decision-makers

For people who are found to lack capacity to make certain decisions, a guardian may be appointed for some or all 'personal' decisions and an administrator for some or all 'financial' decisions. While the guardian or administrator has legal authority to make some decisions on behalf of the individual, under Australian law that authority is limited. As well as being subject to the appointing Tribunal, these substitute decision-makers are obliged to follow the decision-making principles in legislation. In some Australian jurisdictions, these principles explicitly mandate that supported decision-making must be attempted by the substitute decision-maker before a substitute decision is imposed (see below at Section Legislative *principles recognising a supported decision-making approach*). In other jurisdictions there is generally a need to take into account the person's views and wishes.[380]

While there is little that reports on how supported decision-making works where a substitute decision-maker is appointed, one international pilot (discussed below at Section *Supported decision-making pilots – with published results and/or evaluations*) did raise the potential problems encountered when the people fulfilling the roles of an appointed guardian and supporter respectively, were different. The experience from that pilot was that: '[T]he appointment of a supporter concurrently with a guardian was repeatedly proven in the pilot to be ineffectual: the supporter cannot really help the person pursue their wishes when every choice is subject to the guardian's approval, and the supporter's work releases the guardian from their responsibility toward the supported person.'[381]

Domestically, we see evidence of statutory bodies (such as the Queensland Public Trustee (Qld PT) (discussed below at Section Supported *decision-making pilots – with published results and/or evaluations*) who are appointed as last resort guardians or administrators, actively embedding such an approach in their interactions with the people they represent. This demonstrates that, at least in some parts of Australia, supported decision-making and substitute decision-making are not mutually exclusive. Instead, it is consistent with those who view support and substitution as existing on a continuum where the individual's will and preferences remain central to the decision-making process. This approach is acknowledged in the La Trobe Framework which recognises that good supported decision-making that puts a person's will, rights and preferences at the centre of decision-making may be provided by substitute decision-makers. For example, recourse to formal substitute decision-making may need to be sought when there are conflicting views among informal supporters, or potential for significant harm to result from an individual's preferences. In the study of the Qld PT's use of 'structured decision making' (discussed below at Section Supported *decision-making pilots – with published results and/or evaluations*), modelled on the La Trobe Framework, staff are directed to reference the process they have used and principles in the legislation if they propose to override a person's preferences. This helped alert them to the seriousness of such actions.[382]

8.2.2 Self-appointed substitute decision-makers

Many people in Australia have executed legally binding instruments that appoint another person to act on their behalf in the future, at a time when they will be unable to make decisions themselves. These appointments may be in the form of enduring powers of attorney, enduring guardians or advance directives. If the instruments provide for the appointee to make decisions according to the person's 'will and preferences' and not their 'best interests' then they may be consistent with the CRPD Committee's understanding of supported decision-making.[383]

How might supported decision-making be relevant if such an appointment is made? This may depend on what the document says as individuals can dictate the terms of the appointment. However, the extent that they reflect what the person has envisaged may be dependent on the level of effective supported decision-making received from supporters – both informal and professionals (for example, clinicians for advance directives) – at the time the document was executed. As noted by the CRPD Committee, '[s]upport should be provided to a person, where desired, to complete an advance planning process'.[384] As discussed above, the principles which govern tribunal appointed substitute decision-makers and which mandate either expressly or implicitly an approach consistent with supported decision-making, must also be followed. We note that for some people, and particularly older people with dementia, there may be comfort in nominating others to manage their affairs rather than relying on supported decision-making.[385]

8.2.3 Other formally recognised substitute decision-makers

There are a range of other formally recognised substitute decision-making roles that appear in health care (that is, the 'person responsible' and other medical default decision-maker equivalents), within the NDIS (nominees) and Centrelink (payment nominees).[386] These more limited roles may be constrained by decision-making principles in the same way as the substitute decision-makers identified above. However, at least in relation to the 'person responsible' and equivalents, people in those positions are even less likely to be aware of what supported decision-making is and how to implement it as they are not formally appointed. Australian law provides legal mechanisms for medical decision-making when an adult is unable to make their own decisions. When such a situation arises and it is unexpected, medical decision-making will (in the majority of States and Territories) usually be passed to a close family or friend. These individuals are, in the absence of an appointed attorney or valid advance directive, 'deemed' by legislation as the most appropriate person to make medical decisions for a person at that time. Prior to the situation arising, many individuals may have given little though to decision-making on behalf of others or have been provided with guidance about how to make such medical decisions. Without guidance from clinical staff at the time of the decision, it seems highly unlikely that there would be an awareness of the principles that purport to guide decision-making.

With the exception of the Qld PT pilot identified below (at Section Supported *decision-making pilots – with published results and/or evaluations*), there is very limited evidence of how appointed guardians, administrators, attorneys or other formally recognised substitute decision-makers apply or understand supported decision-making in the context of their legally recognised roles.

In the next sections, we outline the main legal supported decision-making mechanism that have been proposed and adopted globally both generally and in the context of mental health legal frameworks. While there appears to be an increasing number of legal mechanisms, some commentators have suggested that this is not a bad thing, as different mechanisms may offer individuals the flexibility that may be needed to craft supports for decision-making that suits their individual needs.[387]

8.3 Legislative mechanisms relevant across disability groups

This section identifies legal supported decision-making mechanisms that predominantly exist in guardianship legal frameworks, rather than mental health legislation. These are potentially applicable to a person with any disability, whereas those discussed in the next section are predominantly designed for people with mental health conditions who may be subject to involuntary treatment orders.

8.3.1 Legislative principles recognising a supported decision-making approach

Some jurisdictions only have guiding principles within their guardianship legislation that require attempts to be made at supported decision-making before moving to substitute decision-making.[388] While not adopting the terminology of 'will and preference', the language used often denotes a supported decision-making approach should be attempted. In Australia, the recently amended guardianship legislation in Queensland requires a 'structured' approach to decision-making that starts with recognising the autonomy of the individual before any resort to substituted decision-making by people appointed to substitute decision-making roles:

> First, the person or other entity must—
>
> (a) recognise and preserve, to the greatest extent practicable, the adult's right to make the adult's own decision; and
>
> (b) if possible, support the adult to make a decision.
>
> Second, the person or other entity must recognise and take into account any views, wishes and preferences expressed or demonstrated by the adult.
>
> Third, if the adult's views, wishes and preferences cannot be determined, the person or other entity must use the principle of substituted judgement so that if, from the adult's views, wishes and preferences, expressed or demonstrated when the adult had capacity, it is reasonably practicable to work out what the adult's views, wishes and preferences would be, the person or other entity must recognise and take into account what the person or other entity considers the adult's views, wishes and preferences would be.
>
> Fourth, once the person or other entity has recognised and taken into account the matters mentioned in subsections (2) to (4), the person or other entity may perform the function, exercise the power or make the decision.[389]

Similarly, as noted in the literature, supported decision-making practice can be cultivated within the current framework of the *Mental Capacity Act 2005* (England and Wales) due to the guiding principles that assume a person's capacity and require that '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'.[390] However, implementation of that Act and its principles were found to be poor, particularly in the context of more complex decisions.[391] Without referencing the Australian and UK models, Kohn argues for the adoption in the US of this relatively minimalist legislative approach. This is in the context of criticising existing US legislation which she views as actually limiting an adult's rights by providing immunity to supporters or in some cases limiting their ability to revoke an existing supported decision-making agreement (see below at Section Critiques *of legal supported decision-making mechanisms*).[392]

8.3.2 Appointment of legally recognised supporters

Reforms to statutorily recognise people in a supporter role, have been one of the more common legal mechanisms of embedding supported decision-making into existing frameworks. Despite calls to dismantle substituted decision-making frameworks, such reforms are often done as an adjunct to, rather than replacement of, substitute decision-making schemes.[393] Examples of legally recognised supporters include: the supportive attorney and medical support person in Victoria;[394] supporters in Yukon, Alberta,[395] Quebec[396] and Texas;[397] assistants in Ireland;[398] and other reforms in European countries.[399]

This type of legally recognised supporter differs from a legally recognised substitute because there is no transfer of 'any legal powers of decision-making away from the person affected'.[400] Instead, such appointments provide supporters with authority to do certain things for the supported person. Supporters may have access to information on the supported person's behalf, or have authority to help the person communicate their decision. The appointments provide more formal recognition for third parties interacting with the person supported and their supporter.[401] Peru's recent reforms allows considerable flexibility for the person who seeks support to create a role that meets their needs. Martinez-Pujalte states:

> The person that establishes the supports decides their form, identity, amount, effects and extension, but they will not have representative [substitute decision-making] functions unless it has been explicitly so decided by the person who needs support.[402]

However, these types of appointments do not assist people with high support needs who are unable to directly organise the support they need.[403]

It is worth noting that these types of appointments can be distinguished from nominated support persons in the mental health setting (discussed below at Section Nominated *supporters/ representatives*). The role described here is usually contained within guardianship legislation and is more specifically directed towards supported decision-making than being a general 'support person' as tends to be the case in the mental health context. However, there are inevitable overlaps in such legally recognised positions.

8.3.3 Appointment of co-decision-makers

A less common legal supported decision-making mechanism has been recognition of 'co-decision-making', where a person is able to appoint a co-decision-maker via a legally recognised document. Unlike a legally recognised supporter, where the decision is legally recognised as that of the supported person, here the decision is recognised as a joint one. For this reason there have been criticisms that it does not comply with the requirements of article 12 CRPD.[404] Co-decision-making has been recognised in laws in Canada and more recently in Ireland.[405] The data on uptake of co-decision in Canada is limited,[406] but in the Irish context it has been suggested that it will be useful in cases of early stage dementia.[407]

Although recommended by the Victorian Law Reform Commission and the ACT Law Reform Advisory Council, no laws have been introduced for co-decision-making in Australia.[408] There is very little empirical evidence on how well co-decision-making operates as a form of supported decision-making, and conceptual concerns have been raised about how this operates in practice.[409] These concerns include: how co-decision making interfaces with existing laws on consent to medical treatment; if and how liability would be apportioned; whether the relationship is fiduciary in nature (ie a relationship of trust and confidence between two people in which one person has a duty to act in good faith for the benefit of the other) and how to safeguard against undue influence by the co-decision-maker. Also relevant is the challenge of adding a new concept into an already complex legal regime, necessitating another layer of community education.[410]

8.3.4 Hybrid models where supporters are appointed

Other forms of legally recognised supporters combine modifications of the two models above, with a lower capacity threshold. These are designed for people with a disability who would not otherwise be able to execute a power of attorney. The well-known Canadian British Columbia Representation Agreement is one such model,[411] as is the recent Austrian Elective Representative (gewählte Erwachsenenvertretung). Representation Agreements combine aspects of a supported decision-making agreements with enduring powers of attorney and provide the person appointed 'a wide mandate to assist in decision-making through to making decisions on the adult's behalf'.[412] They also incorporate the safeguard of having appointed 'monitors', who have oversight of the relationship between the person with a disability and the person appointed.[413]

The Austrian Elective Representation model builds on the British Columbia model but allows the agreement to be tailored. Such tailoring can allow for: supporters to have access to information; for co-decision-making, or for a supporter to have power to 'veto' the supported person's decisions.[414] This model also has safeguards including requirements for registration of such agreements in a central registry and to file annual reports to an oversight authority.[415]

8.3.5 Judicial appointment of supporters

Many jurisdictions that now allow for legally recognised supporters, also allow for judicial appointment of supporters as an alternative to guardians/administrators. This is the case for example in Victoria[416] and also Peru.[417] This legal mechanism has been subject to criticism – as the court/tribunal ultimately chooses the supporter rather than the person with the disability.[418] But it has nevertheless been recognised as a less restrictive option than appointment of substitute decision-makers and more consistent with the goals of supported decision-making.

The 'God man' appointments in Sweden are another version of legally recognised supporters.[419] These appointments are generally made with the consent of the person who will be supported, although exceptions do apply.[420]

8.3.6 Microboards (and other incorporated networks)

The use of a microboards' (sometimes known as 'self-directed support corporation', 'Aroha entity', or 'person centred society'[421]) is another model of support that sits within a legal framework. While informal groups of people supporting an individual with a disability are relatively common (discussed, for example, above at Section 5.1.3 *Circles of support*), such groups can formalise the relationship through incorporation, a practice that has become more common Canada and the US, particularly for people with intellectual disabilities.[422] A microboard has been described as:

> A small (micro) group of committed family and friends…, who join together with the individual to create a non-profit society (board). They support planning, decision-making, setting up and monitoring supports, advocacy and act as ambassadors to connect the individual with their community.[423]

Unlike the legal mechanisms discussed above, the laws relied on here are not guardianship laws, but rather the ability to create an incorporated legal entity. This arguably builds safeguards into the structure of supported decision-making provided to an individual.[424] There is long standing use of this practice in British Columbia (predating the CPRD) with Stainton reporting that over 900 are in existence and that a non-profit agency has regional coordinators to help develop and sustain microboards.[425] Some parents of people with intellectual disabilities establish these structures to enable supported decision-making for their son or daughter in anticipation of the parent's death in the future. However, Browning found that the existence of this type of structure played a 'very limited role' in shaping the process of supported decision-making.[426] Use of microboards is beginning in Western Australia and there are efforts to establish them in other parts of Australia.[427] Nunnelley has found that in the Canadian context, these supporter groups usually have shared values and are formed to address three main issues: individualised funding and service delivery; friendship and community inclusion (sometimes when parents are gone); and person-directed planning and facilitation.[428]

It is worth noting that microboards may be formed for purposes other than promoting supported decision-making (eg friendships, funding administration etc).[429] However, supported decision-making did appear to be a common goal for those whom Nunnelley spoke to in her 2015 Canadian study for the Ontario Law Commission.[430] One benefit identified by Nunnelley was the informal checks and balances that naturally existed in a group of supporters that safeguarded against inappropriate behaviour by supporters.[431] Despite their use in Canada for some time, there is very little evidence on the effectiveness of microboards (and circles of support discussed above at Sections 5.1.3 and 5.3.3) as a supported decision-making tool.

8.3.7 Other legal mechanisms

While less frequently mentioned in relation to supported decision-making, the legal mechanisms of advance directives for health care generally, and the ability to self-appoint future proxy decision-makers such as enduring powers of attorneys, nominees in the context of NDIS, or payment nominees in relation to Centrelink (or representative payees[432] in the US for social security payments) may also prove to be important supported decision-making mechanisms. While many of these are the appointment of a future substitute decision-maker, if chosen by the person and the proxy acts in accordance with the will and preference of the person, it may come within the ambit of a supported decision-making paradigm.[433] This is particularly so if the power is that of being an intermediary or channel of communication, as with correspondence nominees.

8.4 Legislative mechanisms relevant to the mental health context

As specific legal regimes exist in most countries for the provision of treatment for people with mental health conditions particularly during crisis episodes, a range of legal mechanisms have been incorporated into legal frameworks which are, at least partly, concerned with supported decision-making. What we see occurring domestically and overseas are adjustments to mental health frameworks to incorporate aspects of supported decision-making rather than a complete overhaul of current systems of substitute decision-making.[434] More so than in the literature for other disabilities, psychiatric advance directives and other forms of advance planning appointments and independent advocacy have more fully been recognised as tools of supported decision-making.[435]

The following are international examples of legal frameworks in mental health systems that have included supported decision-making options.

8.4.1 Sweden's Personal Ombudsman (PO) Skåne independent advocacy

Since 2001, a Swedish service freely accessible to people with psychosocial disabilities provides for a formal independent advocate who can be legally appointed to assist a person with mental health conditions to make legal decisions.[436] The model is designed to develop trusting relationships for up to 6 months, but it is reported that often longer term relationships are cultivated between the formal PO and the person with a disability. The PO is described by Berggren as occupying, 'a freestanding position, independent of authorities, and reports recurring social issues affecting persons with psychosocial disabilities directly to the national agency for health care and social services'.[437] The PO assists a client to decide how they wish to proceed in relation to current issues they face and then can assist in advocating their perspective to other professionals. The PO can act on behalf of the person.[438] As Gooding reports, part of their role is to 'make demands on the public authorities… to ensure that they are receiving the help and service to which they are entitled'.[439] Berggren reports that research and outcomes of this model are positive, with small qualitative studies indicating the model can assist with client's recovery processes.[440] This is an example of a model that is available to someone who does not have a pre-existing support network. Berggren identifies some risks associated with the model, including lack of scrutiny of those acting as POs (compared with other professions) and how to ensure the POs are sufficiently educated about options available to their clients to provide accurate information of services available.[441] This has been identified as a promising practice that incorporates supported decision-making.[442]

8.4.2 Psychiatric advance directives/statements (PADs)

In the context of people with mental health conditions, PADs are often identified as a feature of mental health legislation that is directed at supported decision-making. For example, recent legal reform work in Zambia,[443] India[444] and the Netherlands[445] situates PADs in the context of supported decision-making, as do recent reforms in the ACT and Queensland,[446] and proposed reforms in Victoria.[447]

A PAD is a document 'designed to convey a person's treatment preferences to their treating clinicians at times when, due to their mental health, their ability to communicate or make decisions might be impaired.'[448] Wide variation exists as to the form and extent to which they are intended to be binding, however, 'all of the models are intended to empower a person and assist in supporting their will and preferences.'[449] Terminology also varies with 'crisis cards' and 'Ulysses directives' coming within the remit of PADs.

A number of issues have been identified with this legal option. One is that there can be a low uptake of PADs.[450] This may be because, as Morrisey notes, supported decision-making may be needed in the process of making and executing a PAD.[451] In addition, in jurisdictions where PADs are unenforceable, people with mental health conditions may be less inclined to execute one knowing that it may be overridden.[452] Alternatively, it has been suggested that how an individual experiences their condition may make them more or less inclined to access PADs.[453] Stone et al suggest that while assumptions have been made about PAD as an effective mechanism of supported decision-making, it may only work or be adopted if people with mental health conditions subscribe to the idea that there is a 'lucid' well self and a different self during a period of illness that should have their wishes overridden via a PAD.[454] From their interviews with twenty-nine people with mental health conditions in Victoria, Stone et al found that participants' views about self-illness were often complicated and did not consistently subscribe to this view.[455] Maylea's small Australian qualitative study on PADs came to the conclusion that 'a flexible advance statements regime that responded to the needs of individuals making advance statements would be expected to both increase the uptake and the usefulness of the scheme.'[456]

There may also be barriers to uptake, particularly in developing countries. In the Indian context, Sharad et al note that 'poor literacy, limited access to information, insufficient knowledge regarding mental health, mental illness, treatment and management options, and lack of human resources' may prove to be significant barriers.[457] Even in developed countries, such as Australia, there is perceived to be a lack of knowledge amongst health care providers which may impede implementation.[458] The ACT has gone some way to addressing this, in legally requiring clinicians to inform people with mental health conditions of the option to make a PAD.[459]

In research conducted in Victoria with people with mental health conditions, family supporters and mental health care professionals (n=32) a preference was expressed by people with mental health conditions to have access to supported decision-making mechanisms such as advance directives (although the study did not indicate how many participants with mental health conditions agreed with this sentiment).[460] This was echoed by some family supporters.[461]

8.4.3 Nominated supporters/representatives

Nominated supporters/representatives have become a relatively common feature of contemporary mental health laws and are often explicitly considered to be a legal mechanism to promote supported decision-making.[462] This is where a supporter is nominated by the person and given certain powers and responsibilities under legislation, such as receiving information about the person, supporting the person and representing their interests. Sometimes this nominated supporter role encompasses substitute decision-making as a last resort, as is the case in India.[463] This role tends to be distinct from general legally recognised supporter roles under capacity based guardianship legislation (see Section *8.3.2 Appointment of legally recognised supporter* above). However, Roper notes that in the context of the Victorian legal framework, a nominated person's 'contributions can be ignored'.[464]

8.4.4 Independent Patient Rights Advisors/Independent Advocates

These are statutorily recognised roles in many mental health legal frameworks (eg Australian jurisdictions such as Victoria[465] and Queensland,[466] Scotland,[467] and England[468]). Their role is predominantly advocacy, but as recognised by Stavert in the Scottish context:

> Access to independent advocacy services is acknowledged as a mechanism through which individuals with mental disorder, whether subject to compulsion under the Act or not, can be supported to make their own decisions.[469]

Their role generally includes communicating with mental health patients to ensure that they know their rights, but also extends to helping them to communicate their wishes to others and provide support in formal proceedings such as Tribunal hearings.[470] Newbigging et al report that in England, uptake of Independent Mental Health Advocate (IMHA) services was variable and while users report satisfaction with positive experiences of advocacy this was not necessarily linked to ‘tangible impacts on care and treatment’.[471]

8.4.5 The Fusion model

A further but controversial legal reform relevant to mental health laws is the proposal to do away with the demarcation between mental health laws and guardianship laws and to create a single scheme where the main threshold for mental health intervention would be a lack of capacity.[472] Capacity would be presumed and mental health treatment would be accessed on the same voluntary basis as for general health care. This is of particular relevance in jurisdictions outside of Australia where laws allow the involuntarily detention of people with mental health conditions in the absence of the need to satisfy any capacity test. This proposal has become known as the ‘fusion model’ and has been adopted in Northern Ireland’s recent reforms.[473] However, as it is not directed to implementation of supported decision-making, this proposal is of limited relevance, other than arguably not being inconsistent with the CRPD despite the monitoring Committee’s declared opposition to it.[474]

8.5 Critiques of legal supported decision-making mechanisms

A significant critique of some of these legally recognised forms of support has been made by American scholar Nina Kohn, who suggests that the proliferation of such legal reforms, at least in the US context where supported decision-making agreements have been the main feature of reforms, is counter- productive to the rights of persons with disabilities.[475] The reforms (which are introduced state by state) largely create legally recognised supporters (see above at Section Appointment *of legally recognised supporters*) within State guardianship frameworks. She argues that the legal reforms of this type, ‘promotes a form of private family ordering that is antithetical to individual rights, consequently exposing individuals with disabilities to substantial risk of exploitation’.[476] Part of the reason why Kohn believes there are risks of exploitation is the lack of safeguards contained in most US legislation. She suggests that the legal reforms have been galvanised by the confluence of interests of three groups:

> Family members of individuals with disabilities, who benefit from the new powers this legislative approach gives them; disability rights advocates, for whom its rejection of professionalized care resonates; and fiscal and social conservatives, who find it attractive because it both reduces public expenditure and embraces a conservative vision of the family as a private, supportive unit that should be protected from government influence.[477]

Others have also queried whether similar fiscal drivers might be at play in the Australian mental health context.[478]

In relation to self-appointed support mechanisms, Carney notes that like other forward planning documents, there is likely to be 'low and differential take-up around race, ethnicity, education and other variables'.[479] Further practical issues identified in the literature regarding some legal mechanisms relate to the difficulty faced by legally recognised supporters in determining when someone's decision-making ability has declined to the extent that supported decision-making (as characterised by legislation that relies on a capacity threshold) no longer works.[480] For formalised support structures, including formally recognised supporters or microboards, there is a concern that some supporters will favour an approach that prioritises safety, minimises risk which can lead to substitute decision-making under the guise of supported decision-making.[481]

Conversely, Wildeman notes that under some legal mechanisms where decision-making authority remains with the person with a disability (for example, where a legally recognised supporter is appointed), there is also a lack of accountability for abuse or exploitation due to the 'formal source of decision remain[ing] with the individual him or herself'.[482] Support of this kind may also need to include effective oversight of supported decision-making arrangements by public bodies, such as Public Advocates.[483]

A further issue identified is the need for clear and easily understandable legal frameworks. In their review of legal frameworks of supported and substituted decision-making Davidson et al noted:

> A central issue across the jurisdictions are the complexities of the legal frameworks. It could be argued that a number of laws using highly specialist language may be necessary to address the range and nature of the issues involved in mental health and mental capacity services. However, even if that is the case, it would seem especially important that laws in this area are clear and accessible. … [T]here would appear to be a central irony that laws intended to promote and protect autonomy are opaque and difficult for service users and carers to understand.[484]

If legislated supported decision-making mechanisms are to be introduced, there is a risk of confusion as to how the different regimes will work or interact.[485] Carney describes the confusion caused by the terminology in the Victorian legislation which adopts the terminology 'supportive attorney' and 'supportive guardian', encouraging people to incorrectly believe that they are substitute decision-makers.[486]

Many also note that legal reforms in and of themselves are unlikely to change everyday practice of support for people with disabilities:

> [w]ithout effective practice mechanisms to build and sustain personal networks and relationships, the core of supported decision-making will be absent regardless of the legal framework.[487]

Legal reforms will often need to be accompanied by funding for community programs to implement the intent of legislation. Without long term programs, the intended benefits of legislation are unlikely to be realised for people with disabilities at whom reforms were aimed. The same is likely to be true of attempts to implement policy without funding. There are also concerns expressed that formalising support relationships in legal frameworks whereby legal duties are attached to the supporter role may ‘place the “bar” too high, deterring less formal involvement’[488] and ‘risk diluting the perceived legitimacy of informal supporters’.[489]

Whatever formal mechanisms are implemented, Australia as a federation will continue to face challenges with introducing consistent measures across the country (something also evident in Canada[490]), as guardianship and mental health legal frameworks lie within the power of the States and Territories.[491] However, aims for consistency also need to be balanced against approaches that take into account particular local factors with wholesale transplanting of systems between jurisdictions without due consideration also likely to present problems.[492]

9. Supported decision-making initiatives

In this section we outline supported decision-making initiatives that have not already been captured above, as well as focusing on recent supported decision-making pilots. We exclude from this section pre-existing programs which have only recently recognised that their models are congruent with a supported decision-making paradigm, some of which are mentioned above (for example, the clubhouse model).

9.1 Informative Guidance

Various forms of guidance have been developed globally to educate and guide people about the concept and practice of supported decision-making. Many of these have been published (sometimes as grey literature) but have undergone no formal empirical assessment or evaluation. Examples of these types of guidance include:[493]

- The **ASK ME** approach has been developed as being suitable for health care decision-making and other contexts. The acronym is based on steps for a model of supported decision-making that adopts collaborative principles: Assess (a person's strengths and deficits); Simplify (the task and decision); Know (the person); Maximise the ability to understand; Enable (tailor the support).[494]
- The Mental Capacity Assessment Support Toolkit **MCAST** in the UK includes information relevant to supported decision-making, but in the context of capacity assessments.[495]
- The **PRACTICAL** resources guide for lawyers produced as a tool for lawyers by the American Bar Association in conjunction with a number of organisations representing the aged and those with disabilities. The acronym stands for: Presume (guardianship is not needed); Reason (identify reasons for concern); Ask (if concern may be caused by temporary conditions); Community (can concerns be addressed in community); Team (does the person have a team to help make decisions); Identify (abilities or limitations in decision-making); Challenges (address challenges faced by identified supports/supporters; Appoint (a legal supporter or surrogate consistent with person's values and preferences); Limit (any necessary guardianship order).[496]
- Provision of **pro forma supported decision-maker agreements**/information have been made available through some organisations, particularly in the US.[497]
- **Guides** for supporters and people with disabilities to determine who might provide support and how support should be provided.[498]

9.2 Tools for identification of support needs

Some tools were identified in the literature that were aimed at assessing the communication or support needs of individuals, rather than providing a framework for how to provide support to a person with disability. The **CODEamb** tool mentioned above (at Section Dementia *(non-legal) supported decision-making initiatives*) was one example of such a tool for people with dementia.

The other tool under this category is the **Supported decision-making Inventory** tool, which is part of a larger ongoing research program in the US. This tool, developed by Shogren et al, is based on a social-ecological approach to disability which understands disability as a 'mismatch between a person's capacity and environmental demands'.[499] The tool aims to assist people with disabilities and their supporters to 'identify decision-making capacities, environmental demands for decision-making, and supports needed for decision-making'. This then allows planning teams who want to implement supported decision-making with people with disabilities a way to understand individual support needed for decision-making and select supports aligned with an individual's 'preferences, interests, values and needs'.[500] A pilot tool covered the areas of 'personal factors inventory', 'environmental demands inventory', and 'decision-making autonomy inventory' and was administered in an interview with a person with disability with support as necessary. This pilot tool was refined through testing with 153 participants, predominantly people with intellectual disabilities (but included some with mental health conditions) and feedback from advocates.[501] Ultimately it appears to provide an overview of areas where more support may be needed and aims to provide information to tailor individual supports for decision-making.

9.3 Supported decision-making pilots – where information is limited

We are aware of pilots and programs that are occurring globally, but some of these appear to be ongoing (with limited published results) and/or publications/reports are not available in English. Researchers connected with these pilots and programs were contacted by our research team in November 2021 and requested to complete a survey to collect more data about current supported decision-making pilots and program. The results of this survey are included with other data in the final report. Those that we are aware of through the literature include:

- *Supported Decision-making and Community Life in Colombia, under Article 12 and 19 of the Convention on the Rights of Persons with Disabilities* – 'The pilot aimed at building a personalized support system designed to contribute to capacity building for decision-making and the encouragement of independent living. This support system also sought to improve relationships with close relatives, the extended family and community'.[502]
- *Support Networks for Decision-making and Community Life* (Peru), 'Its main goal was to promote decision-making support networks for people with intellectual and psychosocial disabilities in order ensure they could exercise of their rights to legal capacity and to live independently in the community. The pilot included 20 adult participants from Lima, 10 with intellectual disabilities and 10 with psychosocial disabilities, as well as their respective family members and other community actors identified as potential supporters.'[503]
- *Persons with Disabilities, the exercise of their legal capacity and decision-making: implementation of supports in different contexts* (Argentina) – 'This project aimed to identify and critically analyze support systems for decision-making based on the daily experience of participants and was conducted with a participatory action research framework'.[504]

- *PADMACS study*: a multi-phase Promoting Assisted Decision-making in Acute Care settings (PADMACs) study aimed at educating health care professionals in Ireland (see above at Section Dementia *(non-legal) supported decision-making initiatives)*. This study appears to be ongoing.[505]

- *PAD Saks Institute Pilot Program* (Mental Health) – This project aims to 'model and assess strategies to use PADs under the supported decision-making paradigm to improve the effectiveness of community mental health services'. This study appears to be ongoing.[506]

- *Self-determined Decision-making Model* – This research has developed a framework to support people with disabilities to learn about decision-making and problem-solving skills. Research is ongoing regarding the effectiveness of this.[507]

- *NDIS Decision Support Pilot Program* – This pilot – which is ongoing – targets NDIS participants who have limited decision-making capacity (due to brain injury or disability) and no existing relationships that provide informal supported decision-making. This pilot that assists those who need support accessing the NDIS appears to be led by different organisations in different states (eg Leadership Plus in Victoria; Brain Injury SA in South Australia).

- *Skilled to Thrive: Support to make decisions that promote personal safety and prevent harm* – the UNSW Social Policy Research Centre for the NSW Council of Social Service, to conducted research with the Sydney Regional Aboriginal Corporation and the Multicultural Disability Advocacy Association of NSW interviewing people with disability and workers to develop a practice guide for workers supporting people with disability to make decisions about personal safety and wellbeing and preventing harm. Have produced a 'Literature and Practice Review' and the 'Tree of Life' practice guide.[508]

9.4 Supported decision-making pilots – with published results and/or evaluations

In this section we have identified known supported decision-making pilots which have published evaluative findings or have publicly available evaluations in English. This section builds upon the findings from an earlier publication in 2017 which assessed Australian pilots from 2010-2015. We have used findings from that paper and built upon this, integrating new information found for this review. That research found that:

> [t]he pilots were small scale, conducted by both statutory and non-statutory bodies, and adopted similar designs centred on supporting a decision maker/supporter dyad. Primarily, participants were people with mild intellectual disability. Themes included: positive outcomes; uncertain boundaries of decision support; difficulty securing supporters; positive value of program staff and support to supporters; limited experience and low expectations; and varying value of written resources. The lack of depth and rigour of evaluations mean firm conclusions cannot be reached about program logics, costs or outcomes of the pilots.

> The pilots demonstrate feasibility or providing support for decision-making rather than resolving issues involved in delivering support. They suggest that some form of authority may facilitate the role of decision supporters, help to engage others in a person's life, and integrate decision-making support across all life domains.[509]

This review has identified a further 12 pilots that have either taken place in Australia since 2015 or have occurred internationally between 2011-2021 and have sufficient publicly available information to conduct an analysis (see Tables 2 and 3).

Table 2 International pilots

International Pilots (2011-2021)	Years
Bizchut pilot Israel (Israel)[510]	2014-2015
Next Step in Bulgaria (Bulgaria)[511]	2013-2014
ZELDA pilot (Latvia)[512]	2014-2016
QUIP pilot (Czechoslovakia)[513]	2009-2017
The Centre for Public Representation and Nonotuck Resource Associated pilot (Massachusetts)[514]	2013-2016
The Virginia Supported Decision-Making Pilot Project (Virginia)[515]	2019
New York Intentional Supported Decision-making pilot (New York)[516]	2015-2021

Table 3 Australian pilots

Australian Pilots (2016-2021)	Years
La Trobe ARC Linkage[517]	2016-2020
La Trobe TAC[518]	2019
La Trobe Queensland Public Trustee (Qld PT)[519]	2020-2021
NSW Public Guardian (NSW)[520]	2016-2017
Vic OPA & VALID (Vic)[521]	2015-2017

Adopting the same method from that 2017 publication, Tables 4 - 9 summarise details of these newly identified pilots. Table 10 and 11 reproduces the original tables from that 2017 publication. Documents referred to in the analysis of the following seven programs are included in the endnotes.

Table 4. Descriptive summaries of Australian supported decision-making pilot programs (2016-2021)

	Vic	NSW	La Trobe ARC Linkage	La Trobe TAC	La Trobe Qld PT
Organisational arrangements	2015-2017. Office of the Public Advocate (Vic) and VALID, Funded by the National Disability Insurance Agency.[522] A separate evaluation (Balandin, S, Frawley, P, & J Watson, (2016) *Oval project evaluation: Interim report December 2016*. Geelong, Australia: Deakin University) was not publicly available	2016-2017. NSW Public Guardian (PG). Funded by NSW Family and Community Services (FACS). Evaluated by Social Policy Research Centre, University of New South Wales.	2016-2020. La Trobe Living with Disability Research Centre as lead institution, Uni Sydney, Uni Melbourne, Qld Uni of Technology. Funded by the Australian Research Council. (No separate evaluation)	2019. La Trobe Living with Disability Research Centre. Funded by TAC Victoria. (No separate evaluation)	2021. La Trobe Living with Disability Research Centre. Funded by the Queensland Public Trustee (Qld PT) (No separate evaluation)

	Vic	NSW	La Trobe ARC Linkage	La Trobe TAC	La Trobe Qld PT
Project features					
Aims	Aimed to explore the potential for volunteers to support the decision-making of isolated NDIS participants.	Aimed to explore supported decision-making in relation to financial issues for people with disability, in particular people with cognitive impairment who were subject to financial management orders. Also provided training and established a community of practice more broadly for service providers (but this component was not analysed further here).	Aimed to develop innovative education resources, and to then investigate the impact of the resources on the practices of decision-making supporters and the person being supported in a randomised control trial in three jurisdictions (Vic, NSW, QLD).	Aimed to train a small cohort of independence claims employees (support coordinators) to apply the La Trobe Support for Decision-making framework approach to their client planning interactions and determine any change in their client interactions consistent with contemporary disability practice.	Aimed to train QPT staff to apply the QPT's Structured Decision-making framework (adapted from the La Trobe Support for Decision-making Framework) and determine any change in their client interactions.

	Vic	NSW	La Trobe ARC Linkage	La Trobe TAC	La Trobe Qld PT
Design	Formation and support to decision-maker who was a participant in the NDIS who did not have an established supporter relationship and a volunteer supporter with no prior connection to participant. Training and mentoring provided to volunteer supporters.	Formation and support to dyads of decision-makers and supporters. Supporters chosen by decision-makers. Most supporters were service providers, family and friends.	Training and mentoring to supporters of people with intellectual disabilities and ABI. Supporters chosen by decision-makers. Most supporters were family and friends.	Training and support to independence support coordinators to implement a supported decision-making approach to their clients with ABIs living in a community setting.	Training for frontline staff, supervisors and non-frontline staff from the QPT to implement a structured decision-making approach to dealing with clients for whom the QPT is appointed as a substitute decision-maker for some financial decisions.

	Vic	NSW	La Trobe ARC Linkage	La Trobe TAC	La Trobe Qld PT
Methods	Recruitment and training of volunteers not previously connected to the decision-maker. One day induction training for volunteer supporters and provision of guidelines. Ongoing mentoring by the program coordinator. Decision-makers had access to training on rights, self-advocacy and decision-making and had contact with the Self-Advocacy Facilitator. Supporters provided regular written feedback on pilot.	Formation of dyad from existing supporters. Program activities based on three way relationship between decision-maker, a supporter and program staff member (facilitator). Facilitator supported dyad to explore and implement financial decisions, arranged financial literacy training if requested, monitoring, and providing SDM resources.	Formation of dyad from existing supporters. Training to supporters on the La Trobe Support for Decision-making Practice Framework consisted of 2 half days/1 day small group workshops followed by up to 6 telephone mentoring sessions.	Trained independence support coordinators on the La Trobe Support for Decision-making Practice Framework via four training components: online pre-training assessment, delivery and evaluation of the face to face training package over 2 workshops, individual mentoring sessions and online post training assessment	In house trainers developed and delivered the training with support from La Trobe staff. They delivered a one day interactive face to face workshop. Training was based on the La Trobe Support for Decision-making Practice Framework but tailored for the legislative environment and needs of the QPT.

	Vic	NSW	La Trobe ARC Linkage	La Trobe TAC	La Trobe Qld PT
Resources	1 Program Coordinator; 1 Administrative Officer; 1 Self-Advocate; unknown how much time dedicated to project.	4 staff members involved; unknown how much time dedicated to project.	1 full time project coordinator; 1 part time research fellow for 2 years.	Unknown.	Unknown.
Nature of decisions	A wide variety of decisions including pursuing further education; decisions regarding purchases for a new home; seeking new employment; changing service providers, seeking medical treatment.	Financial decisions.	A wide variety of decisions including financial decisions.	Decisions that emerged from review or development of clients' plans. Involved a range of decisions including living arrangements, community activities, vocational goals, and financial control.	Financial decisions.

	Vic	NSW	La Trobe ARC Linkage	La Trobe TAC	La Trobe Qld PT
Participants	15 participants in total (disability not stated). 15 volunteer supporters were matched to the participants.	33 participants in total: conditions included intellectual disabilities (17); mental illness (10) and brain injury (5).	55 dyads of a person with intellectual disabilities and a supporter with an additional five supporters of 4 people with high support needs. 27 supporters completed the training and at 25 least one follow up mentoring session. The majority were parental supporters. 27 supporters participated in at least one follow up interview post-training. 21 dyads of people with ABI participated in interviews pre-training but none completed the training.	9 independence support coordinators employed by TAC to manage plans of adult clients with ABI.	164 QPT employees: 164 completed pre-training surveys; 57 completed post-training surveys; 18 completed interviews.

Table 5 Descriptive summaries of international supported decision-making pilot programs (2011-2021) Part 1

	Massachusetts	Israel	New York	Virginia
Organisational arrangements	2013-2016. Centre for Public Representation (non-profit law firm) and Nonotuck Resource Associates (service provider for residential supports). Evaluated by Human Services Research Institute.	2014-2015. Bizchut The Israeli Human Rights Centre for People with Disabilities. Funded by the European Union. (No separate evaluation)	2015-2021. Supported Decision-Making New York (a consortium of collaborating institutions lead by Hunter College/ CUNY includes New York Alliance for Inclusion and Innovation and the Arc Westchester. Funded by New York State Developmental Disabilities Planning Council (DDPC). NB: project ongoing, selected evaluation occurred at year 3. Evaluated by Elizabeth Pell.	2019. The Arc of Northern Virginia (the Arc) and the Burton Blatt Institute at Syracuse University (BBI). Funded by Virginia Board for People with Disabilities. (No separate evaluation)

	Massachusetts	Israel	New York	Virginia
Project features Aims	Aimed to assess the degree to which supported decision-making could maximise independence and identify best practices and factors that can be replicated as models that advance supported decision-making as an alternative to guardianship.	Aimed to develop and formulate a supported decision-making model, run a pilot with people who were currently under guardianship and disseminate that model to community members, professionals and policy makers.	Aimed to develop a Diversion pilot which offers SDM to divert those as risk of guardianship orders; and a Restoration pilot which offers SDM to those with guardianship orders with the aim of restoring their decision-making rights by terminating guardianship order.	Aimed to empower young adults with intellectual and developmental disabilities to develop and implement SDM plans based on their abilities, interests and needs.
Design	Formation and support to decision makers to execute SDM Representation Agreements with chosen supporters (between 2-10 supporters chosen). Range of supporters including relatives, shared living providers, care manager who was a friend. Supporters had pre-existing relationship.	Formation and support to decision-maker who was under or about to be placed under guardianship and a paid (2)/volunteer (9) supporter with no prior connection to participant. Weekly meetings between decision-maker and supporter.	Trained volunteer facilitators assist decision-makers to develop SDM agreement and identify trusted supporters. Facilitators have access to mentors (a person with experience in the facilitation model). 5 pilot sites running.	Formation and support to decision-makers and their chosen supporters with the option of creating a SDM agreement or written document (6 chose this with 4 choosing not to) Creation of general public education information which also educated decision-makers and supporters.

	Massachusetts	Israel	New York	Virginia
Methods	Orientation given to staff who initiated discussions and supported the setting up of agreements and implementation.	Recruitment and training of volunteers not previously connected to the decision-maker. Ongoing individualised mentoring to supporters and regular monitoring of progress. Pilot staff met with guardians/family members of participants five times to educate and enlist support.	Training and mentoring of volunteer facilitators. Facilitators give support via meetings with a decision-maker over 12-18 months to develop a SDM agreement in which a supporter is chosen. Supporter chosen by decision-maker from among existing supporters.	Education materials provided to dyads. Periodic contact with dyads to discuss progress and reflect on what worked well and what did not.
Resources	In the first year, 18 staff contributed to the pilot. In the second year, this dropped to 9 staff (across 2 organisations) contributing.	Two part time supporters. Additional involvement of project director and trainers of supporters.	A fulltime project director, fulltime senior project coordinator, fulltime New York city site coordinator, part time faculty associate mentor for facilitators, part time project assistant.	Unknown.
Nature of decisions	Use of formal decision-making agreement and wide range of decisions including financial.	No information on decision-making agreements. Appeared to encompass a wide range of decisions including financial.	Use of formal SDM agreement (but only 8 executed at time of evaluation). No information on decision included.	No information on decisions included. Was not explicitly limited to any decision types.

	Massachusetts	Israel	New York	Virginia
Participants	8 participants with a disability initially which increased to 9 participants in year 2 of the pilot. Included people predominantly with intellectual disabilities, but a number of other diagnoses including mental health issues and dementia. Some participants had limited vocal expression range but all were able to communicate. Also included 15 supporters.	22 participants reduced to 19 by the end of the project. Participants mainly had a range of intellectual disabilities or psychosocial disabilities or autism. All either had guardians appointed or were about to be placed under guardianship. Also included 22 paid/ volunteer supporters.	At time of evaluation – 79 participants with intellectual and developmental disabilities had signed up for at one of the pilot sites with 10 withdrawing. Only 8 decision-makers had a fully executed SDM agreement.	9 participants in total: disabilities were autism (5), intellectual disabilities (2) or multiple diagnosis (2). Also included 9 supporters.

Table 6 Descriptive summaries of international supported decision-making pilots (2011-2021) Pt 2

	Czechoslovakia	Latvia	Bulgaria
Organisational arrangements	April 2009 to March 2017, by 'QUIP'. Commenced as part of the project *Quality of Life as a Goal* funded by the European Social Fund. Since January 2012, has continued with the *Black and White project*, supported by the Open Society Fund.	1 Sept 2014 to 30 April 2016, 'Resource Centre for People with Mental Disability "ZELDA", implemented 'Pilot Project for Introducing Supported Decision-making in Latvia' Under the European Economic Area Financial Mechanism 2009-2014, programme "NGO Fund" and sub-programme "NGO project measure".	2013-14. Bulgarian Centre for Not-For-Profit Law. (No separate evaluation) (Note this is a sub-component of a pilot that was implemented in Sofia, Blagoevgrad and Vidin in Bulgaria – but no English language outcomes from those pilots are available)
Project features Aims	To prepare individuals for court cases to show that supported decision-making is viable and a no restriction on legal capacity is necessary – or restoring legal capacity	To ensure respect for human rights of persons with mental disabilities (including intellectual disabilities and mental health problems) by introducing supported decision-making as an alternative to restricting legal capacity	Aimed to provide evidence that supported decision-making as an alternative to guardianship is beneficial to the person and society and from an economic perspective.
Design	Social worker would work with clients to map supports and develop skills, and a lawyer would represent the client in court.	A conception of supported decision-making and proposals for legislative amendments were drafted; information exchanged with Czech and Bulgarian partners, training with experts in person-centred thinking and planning, support providers trained, and direct supported decision-making provided.	Assessment of outcomes of supported decision-making based on quality of life tools and use of an 'open questionnaire' to assess level of support needs. Additional analysis of the costs of services used by decision-makers.

	Czechoslovakia	Latvia	Bulgaria
Methods	Individuals needs for support used tools were mapped including through use of the ‘Supports with Intensity Scale’ and person-centred planning, (including use of ‘circles of friends’)	Person centred planning. Support person is existing person in network/family or professional from ZELDA. But must be an existing relationship of trust. Prepared and signed written supported decision-making agreements. Training of supporters. The work of support persons monitored through supervision, coaching/mentoring, dispute solving mechanism and, through the feedback from decision-maker.	Recruitment of people with disabilities who were either part of a pre-existing pilot program or were currently under guardianship. Supporters not recruited, but some family members, social workers and professionals interviewed to obtain data.
Resources	Engaged external social workers, and Legal Aid – also used experts in augmentative and alternative communication and for people with mental illness worked with mental health services or psychiatrists (engaged via social workers).	Support from ZELDA who also trained family members – support persons. Facilitators provided coaching and mentoring.	Unknown
Nature of decisions	Finance, legal, accommodation, services	Legal matters, support in finance management, health care questions (limited to the access to health care), developing everyday skills and developing support network.	NA
Participants	33 case proceedings on behalf of individuals (27 cases where a person with disability was represented; 1 service provider; 5 unspecified)	28 people with mental disability, 55 family members/ support providers.	53 participants in total: disabilities were intellectual disabilities (28), mental health conditions (25).

Table 7 Evaluations of Australian supported decision-making pilot programs (2016-2021)

	Vic	NSW	La Trobe ARC	La Trobe TAC	La Trobe Qld PT
Methods and limitations	Report appears to be based on the reflections of project staff. The project report did not detail methods used. A separate evaluation (Balandin, S, Frawley, P & J Watson, (2016). *Oval project evaluation: Interim report December 2016*. Geelong, Australia: Deakin University) was not publicly available,	Surveys with decision-makers and supporters at the start and end of the project. Interviews with small sample (6) of decision-makers and their supporters at the start and end of project. Interviews with 3 program staff at the end of the project. Detailed case studies were generated by program staff. Observation of a group session involvement decision-makers. Small sample. Short time frame for participant engagement in project (3-7 months). A third of participants exited program early.	Pre and post intervention (training) measures comparison design using mixed methods (quantitative surveys and qualitative interviews (up to 6 pre and post). Survey instruments used were: Melbourne Decision-making Questionnaire; the SDM Confidence Rating; the Decision Support Questionnaire – supporter and decision-maker versions; the Experience Response Questionnaire – Supporter (ERQ-sup). No supporters of participants with ABI completed the training, a number of participants withdrew from the study; not all participants completed the full complement of interviews and/or mentoring; timing of post training interviews and mentoring inconsistent as moderated by availability. Small number of paid supporters participated in training.	Pre and post intervention (training) measures comparison design using mixed methods (quantitative surveys and qualitative interviews). Survey instruments used were: Melbourne Decision-making Questionnaire; the SDM Confidence Rating; the Decision Support Questionnaire (DSQ) – supporter version; the Experience Response Questionnaire – Supporter (ERQ-sup). Pre/post training data was completed by all participants, post training mentoring interview data (for qualitative analysis) was collected from 9 participants and only 5 participants completed the final post-training quantitative data collection. Small sample.	Pre and post intervention (training) measures comparison design using mixed methods (quantitative surveys and qualitative interviews). Survey instruments used were: the SDM Confidence Rating; the Decision Support Questionnaire – supporter version; Limited number of post-training surveys completed and some participants did not complete all answers in the surveys.

	Vic	NSW	La Trobe ARC	La Trobe TAC	La Trobe Qld PT
Outcomes Decision-makers	Positive reports from the participants who undertook training on rights, self-advocacy and decision-making.	Some decision-makers found financial literacy training useful and valued the information given by program staff and supporters. A majority expressed a desire to take on more financial responsibility/have administration order revoked. Increased capabilities in making financial decisions possible when given opportunity to acquire skills and knowledge. Some participants were successful in having administration orders removed.	Not yet fully analysed, but initial indications suggest some were positive about support given, and supporters pointed to increased confidence and growth of decision-making skills.	NA	NA

	Vic	NSW	La Trobe ARC	La Trobe TAC	La Trobe Qld PT
Supporters	Supporters perceptions not reported.	No change in perceptions regarding what made effective support but some supporters noticed positive changes in their relationships with decision-makers including a greater awareness of decision-maker's capabilities. Information about NSWTG processes and facilitation of communication with NSWTG was considered helpful.	Quantitative data showed increased use of strategies that support participation in decision-making and improved use of SDM principles and strategies. Qualitative data showed training acted as a catalyst for reflecting and rethinking perspectives on support, encouraged a more deliberative approach to support, and they perceived their actions led to increased confidence in expressing preferences of the person they supported.	Coordinators confidence in their ability to give support for decision-making increased significantly(n=5); increased use of strategies that support client participation in decision-making (n=5) and improved use of SDM principles and strategies evident in qualitative analysis of mentoring interview data (n=9).	For those participants who did the pre and post surveys: slightly higher confidence in their ability to give support for decision-making; increased use of strategies that align with supported decision-making and decrease in strategies that do not align with supported decision-making. Qualitative data indicated that staff felt more accountable, and were positive about changes and the use of structured decision making.

	Vic	NSW	La Trobe ARC	La Trobe TAC	La Trobe Qld PT
Broader level	A key risk that was identified was the limitation of program staff being able to provide adequate supervision of supporters and participant relationships across large geographical areas.	More financial literacy training/resources and individualised resources were needed for decision-makers and supporters (not just a generic resource kit). More resources needed about practical information to deal with NSWTG, banks and other agencies. Suggests that NDIS funding might be appropriate to enable financial supported decision-making.	Supporters grappled with expecting the person to make the ‘right decision’ and when the person could not fully understand the complexity or implications of the decisions. Supporters moved between controlling, influencing and enabling the person they supported	Training in the La Trobe framework can have a measurable impact on the professional practice of TAC support coordinator staff working with clients with ABI.	Training has led to the framework approach being embedded into the QPT organisation and has resulted in measurable positive impacts in how QPT’s staff report their interactions with their clients.

	Vic	NSW	La Trobe ARC	La Trobe TAC	La Trobe Qld PT
Facilitating factors	The pilot identified successful methods of volunteer supporter recruitment within the community. Some of the resources developed by the project were seen to be useful by participants and/or volunteer supporters.	Program staff ability to undertake a facilitative role in encouraging supported decision-making, involving intensive direct communication with decision-makers and supporters regarding financial decisions. Program staff as a source of information about NSWTG processes and as advocates.	Having a structure and process to follow. Availability of mentoring to work through training as it applied to their own situation and that of the person they supported.	Participants mostly had a decision coping pattern that was characterized by a strong emphasis on Vigilance coping strategies. Participants with this decision coping style were found to be well suited to applying the steps, principles and strategies of the SDM practice framework as it aligned with their personal decision-making preferences.	The training was driven by legislative changes and organisational priorities which enabled training to reach a large number of staff in a relatively short time. Both frontline staff and supervisors had positive attitudes to the training and had reported consistently applying the training in their work.

	Vic	NSW	La Trobe ARC	La Trobe TAC	La Trobe Qld PT
Barriers	Volunteers need a high level of supervision which involved informal contact, formal debriefing and written reporting. This was seen to be crucial to mitigating risks. Project staff had limited availability to conduct all planned tasks for the project. Challenges were raised by having staff from different organisations and locations.	Nature of financial decision-making lead to concern by supporters about their role because 'money was involved' and concerns about future conflict of interest or the participant's decision-making capacity. Problems in finding supporters for some participants who did not have pre-existing supportive relationships.	Time available to supporters to support decision-making, and participate in training, emotional labour and continual focus that good support for decision-making required.	Barriers to effective SDM practice were identified as unpredictable and high workloads; cultural and socio-demographic factors and the presence of co-morbidities in the client; family members or service provider teams discouraging/preventing clients from 'having a voice'; lack of scarcity of community options were a barrier to implementing client's decisions.	Barriers to effective SDM practice were identified as tensions reported by some staff relating to the need to protect people who were vulnerable; high workloads which affected staff ability to always applying the framework.

Table 8 Evaluations of international supported decision-making pilot programs (2011-2021) Pt 1

	Massachusetts	Israel	New York	Virginia
Methods and limitations	Interviews with staff at the end of year 1. Interviews with participants, supporters and staff at the end of year 2. Small sample.	Interviews with 12 (>50%) decision-makers and 6 guardians during the pilot. Interviews with 12 decision-makers, 6 guardians and 3 supporters at the end of the pilot.	Interviews with 20 supporters (out of 69+). Online surveys of pilot program staff and volunteer facilitators.	2-3 interviews with 9 (out of 10) decision-makers and 1 interview with each supporter. Use of the Supported Decision-Making Inventory System (a survey) which examined use of supported decision-making and self-determination.
Outcomes Decision-makers	Increased self-confidence, pride, happiness, trying new experiences, taking more control of health care, and helping others more.	Improvement in decision-making processes (including awareness, understanding, execution), development of self-advocacy abilities, improvement in money management. Proceedings were initiated for removal of guardians for 6 participants.	‘Increased self advocacy, greater self-confidence, a wider array of experiences and trying new things, reduced anxiety and greater happiness.’	Decision-makers involved in the pilot showed improved independence, self-determination and decision-making skills, made better decision and had enhanced quality of life.

	Massachusetts	**Israel**	**New York**	**Virginia**
Supporters	Formalising SDM relationships was a comfort and gave a sense of security that others would be involved in the life of the decision-maker. One family was able to relinquish court appointed guardianship.	Limited information on supporter outcomes.	Some supporters reported no change. Those that did report change noted positive changes: they stepped back to allow decision-maker to make more decisions, it reduced their fears, it increased opportunities for important conversations and the decision-maker increased their voice and communication since starting the pilot.	Survey responses indicate support for the pilot program with 7 out of 9 considering that the decision-maker's abilities to make better decision has improved as has their quality of life.
Broader level	Support for decision-making seen to positively improve the lives of decision-makers and is a viable alternative to guardianship or conservatorship.	Support for decision-making model managed to significantly advance decision-makers ability to understand, make and implement decisions. May be effective for people with different disabilities, at different stages of life. Guardians who were family members indicated increased their knowledge and provided tools to help decision-maker achieve independent decision-making.	Support for decision-making engagement has resulted in reduced concerns that may have led to guardianship orders being sought by 'potential guardians'.	Increased knowledge dissemination about supported decision-making, including to professionals outside of the pilot.

	Massachusetts	Israel	New York	Virginia
Facilitating factors	Formal decision-making agreements facilitated having multiple supporters work together to support the decision-maker. Multiple supporters for each decision-maker worked well as supporters were committed to and had arrangements for regular and ongoing communication.	Formal training and mentoring/counselling of supporters prior to taking on the role of supporter, and while they supported the decision-maker during the pilot. Formal meetings and education to guardians and parents of decision-makers of the alternative to guardianship.	Mentors for facilitators were considered useful, providing oversight and assistance to facilitators. Family members found education about SDM to be useful.	Unknown.
Barriers	Tensions where concerns for safety of the decision-maker led to limitation on decision-maker's choice. For supporters who have dual roles as paid professionals, tension exists between state standards regarding ensuring safety.	Was noted that supporters had difficulty dealing with fluctuating decision-making abilities (due to mental illness).	Difficulty in recruiting and retaining volunteer facilitators. Length of time between initiating and executing a SDM agreement was much longer than expected (12-18 mths vs 6-9 mths). Model does not provide for those without pre-existing supportive relationships.	Unknown.

Table 9 Evaluations of international supported decision-making pilot programs (2011-2021) Pt 2

	Czechoslovakia	Latvia	Bulgaria
Methods and limitations	Assessed level of success in court proceedings by distinguishing between three categories: success, failure and compromise. Also looked at duration of court proceedings, role of expert opinions and causes of failure.	No formal evaluation, but stories of decision-makers are described and analysed to an extent.	Interviews with decision-makers where the following tools were used: Personal outcome scale for persons with intellectual disabilities; WHOQoL questionnaire for persons with psych-social problems; and an ‘open questionnaire’ to determine the support needs of the decision-making. Comparison made between those pre and post taking part in SDM pilots and those who remained under guardianship or in institutions. Small sample and limited time frame for assessing impact of pilot (6 months). Limited data available.
Outcomes Decision-makers	23 cases- 70% were fully successful. 3 cases – compromise (2.7%) 7 cases – original objective not achieved (21.7%) 5% took up to 6 mths; 11% took up to 12 mths; 4% took up to 24 mths, 7% over 2 yrs. Expert opinions on mental disorders were made without consideration of supports.	The possibility to sign the agreement was crucial in several cases, being an important decision by itself - that could give a person a sense of being in control of his or her life. In several cases the agreement helped the decision-maker and non-professional support persons to defend their choices and rights.	Quality of life tools indicate an increase in quality of life, self-determination and improved interpersonal relations from those involved in the pilots for 6 months (regardless of disability). All measures showed higher outcomes when decision-makers lived in the community using supported decision-making compared with in institutions under guardianship

	Czechoslovakia	**Latvia**	**Bulgaria**
Supporters	NA	A network of supporters is beneficial. Often people wish to receive support from a professional because they do not trust family members or friends or they are isolated. ZELDA considers that a professional, trained support person can be a better option for some people.	NA
Broader level	The pilot demonstrated through use of legal aid and social work that new legal reform mechanisms for supported decision-making could be utilised where a structured system of support was implemented and demonstrated to the courts as being appropriate for the situation and needs of a particular person.	Developing the model of supported decision-making demands hard work within the community: reducing stigma, community mobilization, development of community-based services and recruiting volunteers. For existing clients, their relationship with ZELDA improved and deepened.	Analysis indicates a higher cost per intervention in relation to implementing supported decision-making as compared with applying for guardianship. Higher costs were also anticipated for ‘Daycare’ and consultative services. However, overall cost savings were calculated in relation to social service costs, health care costs and that employment in this cohort may increase
Facilitating factors	Success factors listed as: securing support and collaboration of close persons from their existing networks; quality submissions for the court prepared by social worker and lawyer collaboratively; use of appeals within the courts could be effective.	ZELDA was proposing its’ decision-makers choose support persons from RC ZELDA’s employees). Among the advantages of this model were that equal training and skills and shared values and views were expected from each of the professionals. Therefore, the quality of the services provided by the support person was to some extent predictable and measurable.	Unknown

	Czechoslovakia	**Latvia**	**Bulgaria**
Barriers	Some decision-makers were not supported by families who disapproved of their efforts. Some thought that having legal capacity restored would bring no practical benefit. Individuals experienced stress from engaging in court proceedings. Expert medical opinions required by the courts were often inaccurate regarding individuals capabilities and in some cases led to more restrictive orders being made. Unwillingness to cooperate in the mapping of the necessary support by the decision-maker was an obstruction to collaboration. Failing to establish a relationship based on trust with the person well in advance, meant collaboration could not proceed. Systemic barriers including negative societal barriers, lack of support to implement decisions made, lack of access to supported decision-making in some institutions.	Building trusting relationship with newcomers took time. Many of the families were isolated with weak ties with the community. It is very important, though in many cases complicated, to arrange an individual meeting with the person with disability, where he/she could express their opinion, in safe and trustful atmosphere and using his own communication style. The institution of guardianship is too much taken for granted, and it is hard for ZELDA to get direct access to the decision-maker (easy to contact guardian). Sometimes conflicts of interest. Most of natural support persons were family members, namely, mothers, which made it very hard to propose new way of thinking.	NA

Table 10 Descriptive summaries of support for decision making pilot programs (reproduced from Bigby et al, 'Delivering decision making support to people with cognitive disability - what has been learned from pilot programs in Australia from 2010 to 2015', (2017), vol 52(3), Australian Journal of Social Issues, pp 222-40.)

	SA1	ACT	NSW	Vic	SA2	WA
Organisational arrangements	2010- 2012. SA Office of Public Advocate (OPA). Funded by MS McLeod Benevolent Fund & OPA	2012- 2013. ADACAS an advocacy organisation. Funded by Disability ACT.	2013-2014. NSW Office of Ageing, Disability and Home Care; NSW Public Guardian; NSW Trustee & Guardian. Funded by NSW Dept. Family and Community Services.	2013- 2015. Vic OPA. One full time program Funded by Vic OPA and Vic Law Foundation.	2013-2015. Office of the Health and Community Services Complaints Commissioner (SA HCSCC). Funded by SAHCSCC.	2013. WA Individualised Services (Waid). Funded by NDS and WA Disability Services Commission Quality Improvement Grant.
Project features Aims	Aimed to provide early intervention for people at risk of guardianship through an alternative to guardianship, and alternative decision support for people already under guardianship by use supported decision making principles.	Aimed to demonstrate the importance of support for decision making being available to people with complex decision support needs who are socially isolated and for whom there are few expectations about decision making.	Aimed to develop a support for decision making model and practice in the NSW context and promote new ideas about support for decision making.	Aimed to explore a model of support for decision making for socially isolated people without informal supporters and trail the use of volunteer supporters.	Aimed to build capacity in the service system for support for decision making, give greater voice to people with disability and avoid complaints about disability support services.	Aimed to develop support for decision making skills and knowledge among service providers and embed support for decision making as part of quality services in order to give greater choice and control to people with disability.

	SA1	ACT	NSW	Vic	SA2	WA
Design	Formation and support to dyads of decision makers and supporters. Dyad relationships either pre-existing or newly matched by the program. Most supporters unpaid with some form of pre-existing relationship.	Two stage process. First, increasing decision readiness of participants and then formation and support to dyads of decision maker and supporter. Dyad relationships either pre-existing or newly matched by the program. Most supporters unpaid with some form of pre-existing relationship.	Formation and support to dyads of decision making and supporter. Range of supporters including paid service providers, 10/19, family 7/19, friends1/19, paid advocate, 1/19 and coordinator 6/19.	Formation and support to dyad of decision maker and volunteer supporter with no prior connection to participant. No paid supporters all volunteers.	Formation of dispersed dyads of decision making and supporter hosted by different disability service providers. Enablement of facilitators in each service to support dyads in their service. Range of supporters including family members (2/8) and volunteer (1/8).	Skill development of participants, and their existing networks of supporters.

	SA1	ACT	NSW	Vic	SA2	WA
Methods	Formation of dyad from among existing supporters or recruitment of new supporters. Training and regular support to dyad members and regular monitoring of progress.	Coaching in decision readiness for participants. Formation of a dyad from among existing supporters or recruitment of new supporters. Support to members of the dyad and regular monitoring of progress.	Formation of dyad from among existing supporters or recruitment of new supporters. Training and regular support to members of the dyad.	Recruitment and training of volunteers not previously connected to the decision maker. Formation of dyad from volunteers and support to dyad members, primarily supporters. Advocacy and referral for decision makers about implementing decisions.	Training and mentoring of facilitators, organising a facilitators community of practice. Formation of dyad from among existing or recruitment of new supporters, training and regular support to members.	Training workshops, reflective exercises, short term mentoring and development of multimedia guidance materials.
Resources	Three staff; coordinator, peer worker and monitor with interchangeable roles	Two staff; coordinator, 15 hours a week, and monitor 18 hours a week.	Two staff roles; full- time coordinator and several part time facilitators.	One staff; full-time coordinator with back up support from OPA staff.	Two staff roles; a coordinator and several facilitators each located in a different service.	Two staff roles; workshop facilitator and mentor.

	SA1	ACT	NSW	Vic	SA2	WA
Nature of decisions	Use of formal decision making agreement and wide range of decisions included excluding financial.	Use of formal decision making agreement and wide range of decisions included excluding financial but including spending of money managed by others.	Use of informal decision making agreement and wide range of decisions including financial	Use of formal decision making agreement and wide range of decisions included excluding financial but including spending of money managed by others.	Use of formal decision making agreement and wide range of decisions including financial.	No information on decision making agreements. Wide range of decisions.
Participants	32 participants reduced to 26 by the end of the project, included equal proportions of people with intellectual disability and acquired brain injury or neurological disease. Multiple ways into the program.	6 participants. Included people with a wider range of needs than the SA pilot, and people with complex communication needs. Multiple ways into the program.	26 participants reduced to 20 by end of the project. Majority were people with intellectual disability (22) but small number with acquired brain injury or undisclosed impairment. 85% communicated with speech. Multiple ways into the program.	18 participants reduced to 12 by the end of the project. All people with borderline or mild intellectual disability who were socially isolated without existing informal supporter for decision making. Several had guardians. Most participants referred by OPA.	11 participants reduced to 7 by the end of the project. All people with cognitive disability but no further details available. Self-selection into the project by clients of services where facilitators worked.	36 participants no breakdown but likely to have all been people with intellectual disabilities. Self-selected with their existing supporters.

Table 11 Evaluations of Australian support for decision making pilot programs (reproduced from Bigby et al, 'Delivering decision making support to people with cognitive disability - what has been learned from pilot programs in Australia from 2010 to 2015', (2017), vol 52(3), Australian Journal of Social Issues, pp 222-40.)

	SA 1	ACT	VIC	NSW	SA 2
Methods and limitations	Interviews with participants, supporters and staff. Small sample, use of percentages only to report findings rather than raw numbers	Interviews (termed conversations) with six decision makers, survey of supporters and compilation of case studies. Small sample only of decision makers.	Interviews and survey of participants at three time points. Small sample only of decision makers and limited response to follow up interviews and surveys.	Interviews (4) and focus group with 7 supporters (volunteers). Small sample only of supporters.	Interviews and focus groups with decision makers, supporters, trainee facilitators, and supervisors and managers at different levels. Small sample, data from survey of facilitators not used due to low numbers.
Outcomes Decision makers	Increased decision making confidence, skills and self-determination. Greater social capital and community engagement.	Not reported.	Not reported.	Increased understanding of supported decision making. More involvement in decision making about day-to-day, big, medical decisions, and financial (most increased) aspects of their lives.	Increased confidence in decision-making, confidence, better able to communicate gaols and preferences and greater willingness to try new things. Positive and practical outcomes of decisions made (eg. employment, education).

	SA 1	ACT	VIC	NSW	SA 2
Supporters	Changed interactions with decision makers and improved interpersonal relationships.	Not reported.	Changed relationship with decision makers to one of friendship and deeper understanding of their experiences.	Increased understanding of supported decision making.	Better knowledge about the of decision maker.
Broader level	Support for decision making seen as an alternative or to be used as part of guardianship practice	Understanding that support for decision making can work with guardianship	Knowledge about supporting socially isolated decision makers incorporated into other OPA projects.	Not reported.	Impact on decision makers not part of the program, aspects of facilitators work their organisations, such as learning decision making skills, greater listening for meaning and knowledge about support for decision making.

	SA 1	ACT	VIC	NSW	SA 2
Facilitating factors	Formal decision making agreements facilitated communication between decision makers and supporters. Flexibility enabled the coordinator to take on role of advocate for the decision maker. Inclusion of advocacy in supporters' role. Support from co-ordinator for supporters to better understand their role.	Formal decision making agreements facilitated an individualised approach to support. Using advocates enabled decision makers to participate in the project and/ or implement decisions made. Strongly motivated supporters. Participants who have experience of making decisions and are 'decision ready'.	Effective communication to participants about their rights to make decision. Commitment by supports of at least 12 months to the program. Familiarity of supporters with the disability sector. Induction, training, and ongoing support to supporters.	Individual support from facilitators to supporters increased their confidence and capacity to provide support. Support from facilitators with implementation of decisions. Supporters able to commitment adequate time, who were respectful to people with disabilities, had common sense, good communication and advocacy skills and high ethical standards about maintaining privacy and confidentiality.	Stability of facilitators and replacements available to step in if necessary. Support for facilitators through Community of Practice meetings. Supporters with larger social networks enabled participants to identify increased choices. Participants with sufficient cognitive capacity, adequate mental health, a decision to make changes in their lives and with time to commit to decision making.

	SA 1	ACT	VIC	NSW	SA 2
Barriers	Tensions between families and decision- makers when supporters were not family members.	Time and difficulty of identifying and securing supporters. Problems in understanding family dynamics and negotiating their real or perceived authority. Tensions experienced by guardians between their statutory role and supported decision making principles. Difficulties for participants in choosing specific decisions and not seeing themselves as decision makers.	Tensions with roles and expectations of others involved in a decision maker’s life, such as family members or paid support workers.	Supporters did not find written resources useful and these did not reduce their need for individual support from facilitators. Social isolation of participants and lack of decision making experience. Conflict between supporters and with others involved in decision maker’s life, particularly family members.	Social isolation of decision makers and lack of available supporters placed high demand on facilitators to recruit supporters.

9.4.1 Pilot aims

Most of the pilots aimed to identify and implement a supported decision-making model for people with a form of cognitive disability. Five specifically mentioned an aim relating to proving that supported decision-making was an alternative to guardianship. Two pilots (Vic and Israel) aimed to match people with disability to a volunteer supporter who did not have a pre-existing relationship with the individual. Four pilots also aimed to recruit some people who were currently under guardianship or financial administration. The three connected La Trobe pilots aimed to assess the impact of training in the La Trobe Support for Decision-Making Practice Framework (discussed above at Section 5.1.3 *La Trobe Support for Decision-making Practice Framework ('La Trobe Framework')* on people who provide support to people with cognitive disabilities.

9.4.2 Pilot design

Different models of supported decision-making are evident in the different program designs. In the projects which included decision-makers and supporters (eight out of twelve), the majority, relied on the decision-maker identifying their own supporter. The Czechoslovakia pilot used a social worker to assist decision-makers in mapping their existing support networks. The Israel and Vic pilots were the only ones which relied on volunteer supporters who were not known to the decision-maker. The New York pilot differed somewhat in that it adopted a facilitation approach where a volunteer facilitator worked intensively with a person with disability to create a supported decision-making agreement, in which a supporter is identified. The American pilots focussed more on creating supported decision-making agreements as part of the pilot (New York, Massachusetts) or had it as an option (Virginia). Two of the La Trobe pilots (TAC and Qld PT) focussed solely on supporters and the impact of training on them.

9.4.3 Pilot methods

The majority of pilots adopted a similar approach which was to recruit decision-makers and have them self-identify a supporter (or supporters) from their pre-existing networks. Decision-makers and supporters then entered pilots as participants and one or both were provided with information, training and support in implementing supported decision-making in respect of some decisions in their lives (La Trobe ARC Linkage; NSW; Massachusetts; Virginia). The Latvia pilot took a hybrid approach, where existing supporters were relied upon plus employees of ZELDA, a community organisation. In the QUIP pilot in Czechoslovakia lawyers played a key role in presenting evidence of existing support networks to court, to avoid or revoke restrictions on legal capacity.

Some pilots only offered training and mentoring to supporters (La Trobe ARC Linkage, La Trobe Qld PT, La Trobe TAC, Latvia) while others focussed on supporting decision-makers to make supported decision-making agreements (New York). Others provided training and developed resources for volunteer supporters who had no pre-existing relationship with decision-makers (Israel and Vic) or facilitators under the facilitation approach adopted in the New York pilot. The Czechoslovakia pilot appeared not to offer any training, but support networks were mapped out according to the principles of person-centred planning.

While not the focus of this analysis, it is noted that many pilots reported additional community/professional education activities and creation of education resources. These were sometimes aimed at educating the family and friends of the decision-maker (Israel) but also more broadly amongst professionals or the community (see for example: New York, NSW, Virginia, La Trobe ARC, Vic). The NSW training had some similarities to programs in dementia (see above at Section Dementia *(non-legal) supported decision-making initiatives*) and its evaluation based on feedback data from a one day post-training seminar.

9.4.4 Resources

The information regarding resources used in the pilots varied significantly. Some pilots, such as the New York pilot, had significant resources invested in running the pilot. For example, the New York pilot, had full time and part time staff and paid mentors; and the Vic pilot have a project team consisting of four people across two organisations (although the percentage of time devoted to the project were unstated). The Vic pilot recommended that further support for decision-making programs would benefit from having a full time Program Coordinator, a Self-Advocate Facilitator at 0.5 FTE (to facilitate regular contact with participants) and an Administrative Officer at 0.8 FTE. In other pilots, the staff resources allocated were unstated. The Latvia pilot was resourced by a community organisation and the Czechoslovakia pilot by paid social workers and legal aid.

For the two pilots that utilised volunteer supporters, additional resources needed to be invested in identifying and recruiting suitable volunteers. For example, the Vic pilot detailed how volunteer recruitment had been achieved with promotional material, adverts and information sessions hosted to elicit interest in the volunteer roles. Out of 77 people who expressed interest in the role, 23 went on to complete the application and have references checked. 20 people were accepted as volunteers and completed induction training and 18 were eligible to be matched to participants. In total 15 volunteers were matched to 15 participants. That pilot found that volunteers needed a high level of supervision which involved informal contact, formal debriefing and written reporting, all of which have resource implications.

Also relevant to resourcing volunteer programs was the Israeli pilot's conclusion that 'supported decision making services should be remuneration-based rather than volunteer-based.'[523] The Latvia pilot concluded that most of the existing family support person (mothers) were very wedded to their existing practices which made it hard to propose new ways of thinking.

9.4.5 Nature of decision

For most pilots, a wide range of decisions (eg financial and personal) appeared to be within scope. As well as 'everyday decisions' some specifically tackled larger issues such as whether to pursue removal of guardianship or administration. In two Australian pilots (NSW, La Trobe Qld PT) supported decision-making in the context of financial decisions was the main focus of the pilots.

9.4.6 Participants

The participants in some pilot programs included the decision-maker with a cognitive disability and a supporter or supporters (La Trobe ARC; Virginia; Massachusetts, Latvia, Czechoslovakia)). Some projects only included the decision-maker as a participant (NSW, Israel, New York, Bulgaria, Vic), while others only included supporters (La Trobe TAC, La Trobe Qld PT).

People with intellectual disabilities, ABI and mental health conditions were included in a number of projects (for details, see Table 4. Descriptive summaries of Australian supported decision-making pilot programs (2016-2021) and Tables 5 and 6 Descriptive summaries of international supported decision-making pilot programs (2011-2021). With the exception of the Massachusetts pilot, there were no people with dementia included in the pilot projects.

The total number of participants varied significantly, with some pilot having very small numbers (La Trobe TAC: nine supporters; Massachusetts: nine decision-makers; Virginia: nine decision-makers; Vic: 15 participants matched to 15 supporters) and some having larger numbers of participants (La Trobe Qld PT: 164 supporters; New York: sixty-nine decision-makers; Bulgaria: fifty-three decision-makers) although completion of survey instruments and/or follow up evaluation was normally only completed by a much smaller cohort.

9.4.7 Pilot evaluation

Only three pilots had commissioned independent evaluations from professional organisations or universities (New York, Massachusetts, NSW). The two American evaluation reports were authored or co-authored by the same author (Elizabeth Pell). The New York evaluation came mid-way through the pilot and was targeted at answering a discrete number of questions rather than evaluating the pilot as a whole. The remaining pilots had produced final reports which contained some overall findings or evaluation of the project, although the level of detail and rigour in these reports varied significantly.[524] Peer reviewed literature related to the models implemented in the pilots and results from the pilots were only available in English in relation to the ARC La Trobe pilot and the New York pilot (see above).

With the exception of the Bulgarian pilot and the three La Trobe pilots, there was little in the way of rigorous pre- and post-evaluation methods incorporated into designs. These four pilots used existing validated or specially designed quantitative survey tools pre- and post- the pilot intervention to establish whether significant changes were experienced by decision-makers and/or supporters. In the La Trobe pilots, this included tools to indicate whether practices more or less aligned with effective supported decision-making had increased or decreased following the training intervention.[525] This was combined with multiple qualitative interviews over a period of 12-18 months in the La Trobe ARC pilot. While the Virginia pilot mentioned using the Supported Decision-making Inventory System (SDMIS), the results from use of this tool is unclear in the report.

In the other pilots there was a heavy reliance on qualitative interviews with varying numbers of participants from the pilots and/or reflections from the project team as to what appeared to work better or worse. Methods for qualitative analysis in the pilot reports were generally not described, but direct quotes were often relied upon and themes from the interview data (where used) were generally reported. In the Czechoslovakia pilot, success was measured by whether or not the decision-maker avoided legal restrictions on capacity.

9.4.8 Positive outcomes

Most pilots that included decision-makers as participants concluded that there had been a positive impact on the decision-maker. This was determined by quality of life measures in the Bulgarian pilot. However, in other pilots this was determined through qualitative interviews with decision-makers or reported observations from supporters or others around the decision-makers during the period of the pilot. Common outcomes reported for decision-makers were increased self-confidence (Massachusetts; New York); improvement in decision-making skills (Israel, Virginia, NSW); increased self-advocacy (Israel, New York, Virginia) and a feeling of being in control of their lives (Latvia). For a small number of decision-makers, there had been the removal of, or initiation for removal of a guardianship or administration order during the pilot (NSW, Israel, Czechoslovakia). Notably, in the La Trobe ARC pilot, parental decision supporters reflected on the positive impact that changes to their supported decision-making practice had on their sons or daughters, who showed increased participation in decision-making and increased confidence to express their preferences.[526]

Across the pilots, the impact on supporters who were participants in pilots was less pronounced than decision-makers. Some reported positive changes such as reducing supporter's fears or resulting in positive changes in the decision-maker-supporter relationship. In contrast to most pilots, the findings from the La Trobe pilots indicated a significant impact on supporters' confidence and abilities to implement effective supported decision-making in relation to the people that they supported. The La Trobe TAC and Qld PT pilots that worked with professional staff who have responsibilities in relation to clients financial and other matters, demonstrated a quantifiable shift in self-reported behaviour towards effective support practices. As did the parents of adults with intellectual disabilities in the ARC pilot. These changes were evidenced from the results of validated survey tools that were used pre and post intervention. These positive impacts are also demonstrated from the qualitative data reported in the La Trobe TAC and Qld PT final reports and ARC linkage publications.

9.4.9 Barriers and facilitators

A variety of factors were seen to be 'facilitating' the success of supported decision-making in the pilots. The role of staff who acted as mentors (to facilitators or to supporters or decision-makers) was generally viewed positively (Israel, New York, NSW). The Massachusetts pilot found having a formal supported decision-making agreement facilitated having multiple supporters working together to support decision-making. Having supported decision-making as an organisational priority and making training a requirement for most levels of staff at an institutional level had a positive impact in the Qld PT pilot. The availability of mentoring was valued by staff in the TAC pilot, as assisting to apply steps and principles of the supported decision-making framework to their practice. Volunteer supporters in the Vic pilot benefited from guidelines that were developed for them regarding their 'Scope of Practice' and when to contact the project coordinator for guidance.

Significant difficulties were experienced in recruiting participants in some pilots. This was particularly evident in the New York pilot, the NSW pilot, the Vic pilot and for the ABI cohort of the La Trobe ARC. There were also difficulties in recruiting and retaining volunteers in the position of facilitators in New York, and the Israel pilot notes that three volunteer supporters dropped out of the training out of a group of fourteen while 2 withdrew from a group of 20 volunteer supporters following induction training.

The Vic pilot noted that some people with a disability who may need decision support are in crisis 'eg seeking emergency accommodation' and while supported decision-making is needed, 'they are not in [a] position to be able to establish a new relationship in their life'. It also found that that some individuals who have 'complicated lives involving conflict' or who needed professional advocacy were not successfully matched to a volunteer. It is possible that volunteer schemes may, when in place, reach a proportion of those who do not have pre-existing supporter relationships, but may not be suitable for everyone.

The Latvia pilot found that developing supported decision-making demands hard work from the broader community to reduce stigma, mobilise the community and develop services and also that building a trusting relationship between the decision-maker and a ZELDA employee took some time. The Czechoslovakia pilot noted that some decision-makers were not supported by families who disapproved of their efforts, and many of the decision-makers found court proceedings very stressful.

Other barriers are noted in Table 7 Evaluations of Australian supported decision-making pilot programs (2016-2021) and Tables 8 and 9 Evaluations of international supported decision-making pilot programs (2011-2021).

9.4.10 Discussion of pilots

Since 2011 internationally, and since 2016 domestically, we located 12 supported decision-making pilot projects. This is in addition to those identified above (at Section Supported *decision-making pilots – where information is limited*) where published information is not available in English. While previous pilots (reported in Bigby et al[527]) centred on similar models of decision-maker supporter dyads, these newly identified pilots demonstrate more variability in the models of supported decision-making adopted. There are also more sophisticated analyses being undertaken, as evident from the Bulgarian cost-benefit analysis, which attempts to answer the question of whether supported decision-making can result in societal cost savings; and the La Trobe pilots which are creating a significant evidence base that demonstrates that training can have a measurable impact on supporters' confidence and strategies adopted when providing supported decision-making – whether in a professional or informal context. However, for most evaluations, the conclusion drawn in relation to prior pilots is still largely applicable: the 'lack of depth and rigour of evaluations mean firm conclusions cannot be reached about program logics, costs or outcomes of the pilots.'[528]

Also evident is a more explicit consideration of whether supported decision-making is a viable alternative to guardianship or financial administration orders, with pilots in America, Israel, Czechoslovakia and NSW examining this, and more pilots seeking to recruit participants who have guardianship or financial administration orders in place. Although evidence of this from the pilots remains scant given the low numbers of relevant participants.

The vast majority reported positive outcomes for decision-makers who participated in pilots. In some cases, the impact in improving quality of life for these decision-makers was quantifiable due to use of validated Quality of Life survey tools (Israel). Program staff who provided mentoring or other supports were often viewed as an important facilitating factor in the success of pilots. This has implications for the cost of funding these types of programs on ongoing basis and will need to be considered if the practice is expected to continue beyond the life of funded pilots.

While a reliance still remained on participants self-selecting a supporter in most pilots, the Israel, Latvia and Vic model of using trained volunteer supporters with some reported success is important. If supported decision-making is to be made available to those people who need and want it, there needs to be the option of choosing someone whom they already know or having the alternative of finding and getting to know someone who will act in that role. This is necessary if the significant concern raised in the literature (see below at Section 10. *Problems and the need for safeguards*) about people with disabilities who have no pre-existing supports is to be addressed. The Israeli and Latvia pilots recognised the need for trust to be built between proposed volunteer supporters and decision-makers in order for effective support to be provided. The Israeli pilot noted a number of 'practical tools' for enabling this to occur, including: meeting the person at a location meaningful to them; developing clear and open communication based on respect honesty and non-judgement; meeting with the decision-maker's confidants or those who play a significant role in their life; building relationships through shared activities; and the supporter being prepared to learn from the person and 'welcome mutual exposure'.[529] Similarly, the Vic pilot noted that it took 'considerable effort to identify and engage with isolated participants' and their pilot utilised a 'structured process' of matching participants and volunteers based on factors such as personal preferences (age, gender, location etc), interests, level of support required/willing to be provided, personality type and availability. It also suggested that targeted volunteer recruitment in response to the particular needs of decision-makers may be more effective.

While peer reviewed outcomes from the nine pilots remain limited, collectively there is an increasing evidence base that enables claims to be made about the effectiveness of supported decision-making on the lives of people with disabilities.

In considering these pilots, we should also take account of the local context in which they were run. As noted by Mahomed et al in their review of current programs and research:

> …supported decision-making regimes need to be contextually relevant, recognizing the significance of local resource availability and cultural norms that may have a bearing on relationships and relational autonomy… further efforts [are needed] towards innovation and development of contextually relevant models, rather than wholesale importation of existing approaches.[530]

It can be challenging to compare models and results between jurisdictions where cultures, service systems and legal frameworks significantly differ.

10. Problems and the need for safeguards

The critiques of formalising supported decision-making within legal frameworks have been discussed above (at Section Critiques *of legal supported decision-making mechanisms*). Here, a number of potential problems with supported decision-making generally are considered, leading to a discussion of the safeguards needed in practice.

10.1 Problems identified with supported decision-making

A common issue identified in the literature is the possibility of manipulation, undue influence or de facto substitute decision-making by people acting as supporters.[531] The CRPD Committee noted that undue influence may be present where interaction between supporters and the person being supported 'includes signs of fear, aggression, threat, deception or manipulation'.[532] As noted by Kohn:

> One of the primary worries, even for those advocating supported decision-making, is the potential for coercion or other inappropriate influence by a representative or supporter. Exploitation and abuse certainly occur in guardianship contexts (although it is unclear how frequently), and supported decision-making arrangements create new opportunities for abuse. Indeed, when we turn to more informal arrangements such as supported decision-making, which may occur in private and with less accountability, the potential for financial or other abuse likely increases.[533]

Kohn and Blumenthal also write that without more evidence it may be that *informal* supported decision-making actually disempowers adults by allowing undue influence. They contrast this with guardianship in the US, which has more accountability.[534] Scholten et al also suggest that in medical decisions undue influence is likely to be a greater issue under supported decision-making arrangements than in substitute decision-making arrangements due to the 'untransparent and potentially unfair distribution of responsibility'. They argue that the checks and balances that are normally present when substitute decisions are made are absent in a regime where decision-making authority purportedly remains with the individual.[535]

Nedlund, describing supported decision-making for people with dementia in Sweden, notes that it is unregulated and because of that, the right to self-determination actually risks being over-ridden. In an unregulated environment this problem remains hidden, and there may be 'grey' areas where family and professionals exercise their discretion unchecked.[536] Indeed, as noted by Flavin, for a person experiencing dementia, undue influence and paternalism are often presented as compassion or support, when in reality the 'supporter' is dictating what a person must do and when.[537]

In addition, formalised supported decision-making arrangements also raise concerns. Suggestions have been made that, even if made available, self-appointed supporter mechanisms may not be well used. There are concerns about low levels of interest and 'differential take-up' due to factors such as ethnicity and levels of education.[538] The very nature of a private, self-executed supported decision-making agreement, often implemented in family settings, mean that it may serve to 'insulate' such relationships from scrutiny and 'magnify the risks of their deliberate abuse'.[539]

There is also the suggestion that supported decision-making arrangements – whether formal or informal – may have a 'net widening' effect.[540] A proliferation of suggested or implemented legal reforms, may result in more adults being subject to regulation and scrutiny than under existing guardianship regimes.[541] In informal as well as formal spheres, supported decision-making may expand expectations 'that control or authority over fundamental personal decisions be shared with family members or others'.[542]

There has also been some concern expressed, particularly in the mental health context, that implementing supported decision-making may lead to the withdrawal of other supports that people may need or benefit from. Mattsson et al discuss similar problems in the Swedish system where no one has legal power to make decisions other than the adult. As a consequence, some adults with cognitive disabilities may not get supports to which they are entitled.[543] Australian research has found that people with mental health conditions and family supporters also articulate this concern with Brophy et al noting that there are: '…fears that increased emphasis on SDM would result in reducing the number of people on [Community Treatment Orders], which could lead to consumers being subsequently abandoned by service providers.'[544]

While some supported decision-making pilots have sought to train volunteers to act as supporters, the lack of viable options for people with disabilities who have no existing network of family and friends upon which to draw remains a significant problem.[545] An issue of inequity arises here, as well-resourced individuals with strong social networks may benefit from supported decision-making, while those without networks will miss out.[546] This may be a particular problem in residential aged care facilities or group homes for people with intellectual disabilities where social isolation has been exacerbated since the COVID19 pandemic.[547]

Other issues relate to barriers to implementation of supported decision-making practices. There is a clear need for training of potential supporters in the service system contexts identified above (at Section 7. *Service system contexts of supported decision-making*) as well as in other sectors such as banking.[548] In addition, education and training for informal supporters is needed.[549] However, this will only occur with appropriate funding for such initiatives, which is rarely acknowledged by governments or made available.[550]

10.2 Safeguards

The need for safeguards against abuse in supported decision-making is explicit in article 12(4) CRPD. As noted by Snelling and Douglas:

> The design of these safeguards raises procedural issues, regarding how to provide appropriate oversight and protection, and substantive issues, such as determining when a support person's influence becomes "undue", and what constitutes exploitation.[551]

Various types of safeguards have been suggested both within and outside formal legal frameworks.

10.2.1 Safeguards in legislation

Most safeguards identified in the literature focus on imposing responsibilities, control and oversight on the supporter role,[552] recognising that supporters and people being supported are often in unequal relationships. However, as noted by Bartlett: 'how it is to be done is at best unclear, without the development of a system that is both unwieldy and intrusive'.[553] In some jurisdictions, including US States and Ireland, restrictions have been placed on who can act as a legally recognised supporter.[554] This purported safeguard attempts to decrease the risk of exploitation or manipulation of decision-makers by supporters. For example:

> Some states, like Delaware, Alaska, the District of Columbia, and Rhode Island, restrict who may serve as a supporter. This includes employers/employees, anyone against whom the decision-maker has a restraining order, and individuals directly providing paid support services to the decision-maker.'[555]

Strategies have also included making explicit in legislation the duties on supporters to, for example, refrain from undue influence;[556] or expressly making the supporter relationship one which comes with fiduciary duties.[557] This can also involve the need to submit periodic reports to a government body with oversight responsibilities of supporters (as is the case in Ireland).[558] Another legislative safeguard is to provide access to both periodic and on-request court or tribunal review of support arrangements. The importance of this has been highlighted in the context of the Argentinian reforms, together with the importance of the supported person's right to be heard on their own, or with support.[559] An interesting innovation that places the issue of safeguards in the hands of the person with a disability exists in Peru, where people can nominate their own safeguards including reporting, audits, periodic supervision, interview and information requests.[560]

A safeguard in the British Columbia supported decision-making framework is the ability to appoint a monitor – a person who can oversee the supported decision-making relationship.[561] The potential for reliance on a larger group of people to ensure appropriate conduct has been raised in various contexts[562] and may be a useful mechanism that can be implemented informally (see below at Section Non-legal *safeguards*).

The establishment of formal registers of support agreements[563] or dedicated agencies or government bodies to assist in oversight of supported decision-making have also been suggested.[564] For example in Ireland, any person can report an assistant, co-decision-maker or representative to the Decision Support Service if they think they are acting inappropriately. The Decision Support Service has power to investigate the complaint and apply to the court for a determination on the matter.[565]

Other suggested legal safeguards seek to be more facilitative, with suggestions that education and supervision of supporters should be included in formal frameworks.[566] In a similar vein, Sinclair et al suggest that supporters need assistance and education and existing advocacy services need increasing.[567]

Beyond duties imposed directly by legislation, legal frameworks may establish regulatory systems of standards which may more readily recognise aspects of supported decision-making within particular sectors. One example is the Aged Care Quality Standards framework in which Standard 1 (Consumer dignity and choice) recognises that: ‘consumers who need support to make decisions are expected to be provided with access to the support they need to make, communicate and take part in decisions that affect their lives’.[568]

10.2.2 Non-legal safeguards

There is a recognised need for safeguards in the space of informal supported decision-making. In this ‘private’ space concerns arise with respect to inappropriate and unaccountable actions by purported supporters.

As already mentioned, one suggested safeguard relies on a group of supporters, or a person who is not a supporter but has oversight of supporter activities, ensuring that everyone acts appropriately.[569] Carney has suggested that legislation may not be required and such circles can be:

> … overseen simply by the advocacy, service protocols, health and welfare professional standards and other processes of the myriad of informal community, self-help, non-government and government human services agencies[570]

However, as he and many others recognise, informal supporters need access to information and training to provide effective support. Bigby et al have conceptualised their training for supporters (whether informal or not) as being underpinned by the principle of ‘reflection and review’.[571] Training on this aspect relies on self-reflection by supporters on the appropriateness of their support practices:

> Supporters need to employ a self-questioning strategy, applying self-checks and balances to each decision situation, and remain vigilant to points where they are particularly vulnerable to providing biased, value-laden or constrained support… [S]upporters should be open to review by others, able to articular their reasoning processes, describe observations, experience and knowledge they have used to inform their support and track this through to the point of decision.[572]

The ‘accountability’ that comes from having a process to guide decision-making and principles to govern the process was commented on in the context of the Qld PT pilot. There Qld PT staff act in the role of substitute decision-makers for financial decisions of their clients. However, recent legal change requires supported decision-making to be attempted before any substitute decision are made on behalf of clients. The qualitative data from that pilot revealed that having to document decision-making processes against the framework helped make decisions accountable and could be used to ‘check’ whether there might be a less restrictive approach.[573]

The knowledge that third parties may hold supporters accountable, that is, require supporters to explain processes of support and how decisions were made may also help to create a culture of accountability. In Bigby et al's study, the authors suggest that such external monitoring, which could help to reinforce effective supported decision-making, is largely absent from Australian service systems such as the NDIS.[574]

The pilots discussed above (at Section Supported *decision-making pilots – with published results and/or evaluations*) also demonstrated the value that supporters placed in paid staff who offered mentoring sessions or were available to discuss issues they faced in their role as supporters to a person with a cognitive disability. Given the complexity of the relationship between the supported person and the supporter, these types of internal and external checks on support practices may ensure that support provided to an individual stays within the realms of what is considered acceptable.

There is also a need to recognise that decisions about safeguards from abuse and neglect in a person's life need to involve the person to whom the safeguards are intended to apply.[575] Ottman's Australian qualitative study with 12 adults with mild intellectual disabilities found that participants in that study were able to identify potential risks and safety issues and discuss measures that could be employed to keep them or someone else safe. Their responses were grounded in their own lived experience and participants were found to strategically use support workers or informal carers in their decision-making process. They conclude that: 'it would appear that trusted relationships should form an integral part of a co-created and individualised approach to safeguarding.'[576]

11. How does supported decision-making reduce the risk of violence, abuse, neglect and exploitation?

The current literature does not provide clear answers to the question of whether and how supported decision-making may reduce the risk of violence, abuse, neglect and exploitation of people with disabilities. At its most simplistic, it is argued that supported decision-making offers a way to safeguard against abuse, neglect, exploitation and conflicts of interest that may be present when substitute decision-making occurs.[577] For example, in the context of mental health, if supported decision-making replaces or lessens the reliance on involuntary treatment – including forced medication, solitary confinement or chemical, physical or mechanical restraint – then it may reduce the risk of these interventions. Brophy et al, cautiously suggest that supported decision-making in Victoria may contribute to:

> reducing the use of CTOs, encouraging less use of coercive practices, and improving the experience of people who are subject to these orders through greater respect for their view and preferences.[578]

Another suggestion is that enhancing individual control, making relevant information available and providing more autonomy to individuals, can lead to people with disabilities being less susceptible to forms of abuse. This was the conclusion drawn from research conducted with people with intellectual disabilities in relation to financial abuse.[579]

One situation which has raised practice concerns in the context of dementia, has been the use of restraints. Allen and Tulich argue that embedding supported decision-making in practice and in legal frameworks may create an environment which foregoes the need for restraint decisions to be made for people with dementia.[580]

Another potential way in which supported decision-making may guard against risks of violence, abuse and exploitation is, is through having a group or network of supporters around an individual. As noted above (at Section Microboards *(and other incorporated networks)*), such a group of supporters may guard against the risk of individual or primary supporters acting inappropriately. In addition, the presence of multiple supporters who share a trusted relationship with the individual, provides multiple avenues for intervention, help-seeking and sharing of confidences. The very fact of having multiple supporters means that the individual should be less socially isolated and less likely to be preyed upon by those who may inflict abuse.

In addition, the literature does demonstrate that increased participation in decision-making is associated with increased wellbeing of the decision-maker.[581] It may therefore follow that supported decision-making is beneficial and, by extrapolation, may counter risks associated with neglect and exploitation. However, there is limited evidence to support such claims.

While there is little evidence about the extent to which supported decision-making reduces the need for formal substitute decision-making appointments, it is possible that where it is successfully applied, this will reduce the need for formal appointments. Some pilots (discussed at Section Supported *decision-making pilots – with published results and/or evaluations*) have begun to examine if supported decision-making is a viable alternative for legal appointments which formally remove the decision-making rights of people with disabilities. Preventing the removal of decision-making rights from people with disabilities will reduce the risk of exploitation that accompanies having a substitute decision-maker formally appointed to make decisions on behalf of a person.

Supported decision-making has also been flagged as a mechanism for potentially helping to address elder abuse,[582] a particular concern for people with dementia and older people with disabilities. This was noted in the 2017 ALRC Report on elder abuse.[583] However, as noted by Strickland et al in their 2021 integrative review, gaps in the strength of the evidence on the effectiveness of supported decision-making in older people experiencing abuse mean that no conclusive advice can be provided at this stage regarding whether supported decision-making can assist people experiencing elder abuse.[584]

12. Concluding comments

The literature on supported decision-making is a large and growing body of work. This review has shown that supported decision-making is a promising mechanism to support the realisation of rights by people with cognitive disabilities. It underpins self-determination and autonomy which are key domains for quality of life, and exercise of rights, which are in turn fundamental safeguards against violence, abuse, neglect and exploitation.

However, it also identified significant gaps in the literature in the context of certain Australian communities and supported decision-making – First Nations peoples with disabilities; people with disabilities from culturally and linguistically diverse communities; and people who are LGBTIQ and have disabilities.

Pilot programs continue to innovate, implementing different models to enable or improve supported decision-making for people with disabilities. Gaining more empirical evidence about the connections between the quality of life, and exercise of rights will be possible when supported decision-making programs are more firmly embedded in legislative and service system frameworks and reach a broader range of people over a longer period than the current pilots have done.

Endnotes

1 Jennifer A Byrne, ‘Improving the peer review of narrative literature reviews’, (2016), vol 1(1), *Research Integrity and Peer Review*, 12.

2 Office of the Public Advocate (Qld), *Decision-making Support and Queensland’s Guardianship System: A Systemic Advocacy Report*, 2016.

3 See Shih-Ning Then, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1), *Sydney Law Review*, pp 133–66.

4 Lise Barry & Susannah Sage-Jacobson, ‘Human rights, older people and decision making in Australia’, (2015), vol 9, *Elder Law Review*, pp 1–21; Shih-Ning Then, Terry Carney, Christine Bigby & Jacinta Douglas, ‘Supporting decision-making of adults with cognitive disabilities: the role of law reform agencies – recommendations, rationales and influence’, (2018), vol 61, *International Journal of Law and Psychiatry*, pp 64–75; Michelle Browning, Christine Bigby & Jacinta Douglas, ‘Supported decision making: understanding how its conceptual link to legal capacity is influencing the development of practice’, (2014), vol 1(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 34–45.

5 *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 15 (entered into force 3 May 2008).

6 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174

7 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, 2014.

8 Bruce Alston, ‘Towards supported decision-making: article 12 of the Convention on the Rights of Persons with Disabilities and guardianship law reform’, (2017), vol 35(2), *Law in Context*, pp 21–39.

9 See eg Bruce Alston, ‘Towards supported decision-making: article 12 of the Convention on the Rights of Persons with Disabilities and guardianship law reform’, (2017), vol 35(2), *Law in Context*, pp 21–39; Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third reports of Australia (Advance Unedited Version)*, UN Doc CRPD/C/AUS/CO/2–3.

10 Participant numbers are based on unpublished analysis of the NDIS Data and Insights data cubes (as at 31 December 2019). Data was downloaded from https://data.ndis.gov.au/data-downloads

11 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014).

12 Rosie Harding & Taşcıoğlu Ezgi, ’Supported decision-making from theory to practice: implementing the right to enjoy legal capacity’, (2018), vol 8(2), *Societies (Basel, Switzerland)*, p 25, doi:10.3390/soc8020025; Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’, (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3; Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, ‘The temporalities of supported decision-making by people with cognitive disability,’ (2020), *Social & Cultural Geography*, DOI: 10.1080/14649365.2020.1829689

13 Allison R Heid, Lauren R Bangerter, Katherine Abbott & Kimberly Van Haitsma, ‘Do family proxies get it right? Concordance in reports of nursing home residents’ everyday preferences’, (2017), vol 36(6), *Journal of Applied Gerontology*, pp 667–91.

14 Cf Daniel Bianchi, ‘Advance directives: addressing the obligations of support as part of the right of a person with disabilities to equal recognition before the law?’, (2020), vol 70, *International journal of law and psychiatry*; Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014).

15 Magenta Simmons & Piers Gooding, ‘Spot the difference: shared decision-making and supported decision-making in mental health’, (2017), vol 34 (4), *Irish Journal of Psychological Medicine*, pp 275–86; note also in the mental health context shared decision-making encouraged by the Decision Support Centre approach developed by Midwestern US cited in Susan Campbell, Karen

Stowe & Elissa M Ozanne, 'Interprofessional practice and decision support: an organizational framework applied to a mental health setting', (2011), vol 25(6), *Journal of Interprofessional Care*, pp 423–7. In the dementia context shared decision-making is widely recognised and considered to be beneficial, with decision aids such as pamphlets, books, videos etc found to be useful in providing relevant and structured information John Carmody, Victoria Traynor & Anna Steele, 'Dementia, decision aids and general practice', (2015), vol 4 (5), *Australian Family Physician*, pp 307–10; Kari Lislerud Smebye, Marit Kirkevold & Knut Engedal, 'How do persons with dementia participate in decision making related to health and daily care? A multi-case study', (2012), vol 12(1), *BMC health services research*, pp 241–241; Rachel Louise Daly, Frances Bunn & Claire Goodman, 'Shared decision-making for people living with dementia in extended care settings: A systematic review', (2018), vol 8(6), *BMJ Open* e018977–e018977; more generally see Carmelle Peisah, Oluwatoyin A Sorinmade, Leander Mitchell & Cees M P M Hertogh, 'Decisional capacity: Toward an inclusionary approach', (2013), vol 25(10), *International Psychogeriatrics*, pp 1571–79; Lyndsey M Miller, Carol J Whitlatch & Karen S Lyons, 'Shared decision-making in dementia: a review of patient and family carer involvement', (2016), vol 15(5), *Dementia*, pp 1141-57.

16 Glyn Elwyn, Dominick Frosch, Richard Thomson, Natalie Joseph-Williams, Amy Lloyd, Paul Kinnersley, Emma Cording, Dave Tomson, Carole Dodd, Stephen Rollnick, Adrian Edwards & Michael Barry, 'Shared decision making: a model for clinical practice', (2012), vol 27(10), *Journal of General Internal Medicine: JGIM*, pp 1361–67.

17 See for example: Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, (2017); Paul S Appelbaum & Manuel Trachsel, 'The doctrine of informed consent doesn't need modification for supported decision making', (2021), vol 21(11), *The American Journal of Bioethics*, pp 27–9.

18 Scottish Independent Advocacy Alliance, *Principles and Standards for Independent Advocacy*, Scottish Independent Advocacy Alliance, 2008, p 36.

19 See for example, Anne-Marie Callus, 'Removing obstacles to equal recognition for persons with intellectual disability: taking exception to the way things are', (2018), vol 12(3), *Alter*, pp 153–65.

20 Connie Lyle O'Brien & John O'Brien, 'The origins of person-centred planning: a community of practice perspective' in John O'Brien & Connie Lyle O'Brien (ed), *Implementing person-centered planning: volume II*, Inclusion Press, 2002.

21 Tiago Jesus, Christina Papadimitriou, Felicity Bright, Nicola Kayes & Cheryl Cott, 'What person-centered rehabilitation means in concept and practice: the person-centered rehabilitation model for adult physical rehabilitation derived from a scoping review and thematic synthesis', (2021), vol 102(10), *Archives of physical medicine and rehabilitation*, pp e116–e116.

22 The Health Foundation, *Person-centred care made simple: what everyone should know about person-centred care*, (2016), p 7.

23 The Health Foundation, *Person-centred care made simple: what everyone should know about person-centred care*, (2016), pp 7-8.

24 See: Karrie Ann Shogren, Michael L Wehmeyer, Jonathan Martinis & Peter David Blanck, *Supported decision-making: theory, research, and practice to enhance self-determination and quality of life*, Cambridge University Press, 2019.

25 Edward L Deci & Richard M Ryan, 'Self-determination theory' in J D Wright (ed), *International Encyclopedia of the Social and Behavioral Sciences*, Elsevier Ltd, 2015, pp 486–91.

26 Karrie A Shogren, Michael L Wehmeyer, Susan B Palmer, Anjali J Forber-Pratt, Todd J Little & Shane Lopez, 'Causal agency theory: reconceptualizing a functional model of self-determination', (2015), vol 50(3), *Education and Training in Autism and Developmental Disabilities*, pp 251–63.

27 Brian H Abery & Roger J Stancliffe, 'Ecology of self-determination' in D J Sands & M L Wehmeyer (ed), *Self-determination across the life span: Independence and choice for people with disabilities*, Paul H Brookes Publishing, 1996, pp 111–46.

28 Lucy Knox, Jacinta Douglas & Christine Bigby, 'Becoming a decision-making supporter for someone with acquired cognitive disability following traumatic brain injury', (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities,* pp 12–21; Christine Bigby & Jacinta Douglas, 'Supported Decision Making' in Roger J Stancliffe, Michael L Wehmeyer, Karrie A

Shogren & Brian H Abery (ed), *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan*, Springer International Publishing, 2020, pp 45–66; Deirdre Fetherstonhaugh, Laura Tarzia, Michael Bauer, Rhonda Nay & Elizabeth Beattie, '"The red dress or the blue?" How do staff perceive that they support decision making for people with dementia living in residential aged care facilities?', (2016), vol 35(2), *Journal of Applied Gerontology*, pp 209–26; Craig Sinclair, Sue Field, Meredith Blake & Helen Radoslovich, 'An examination of organisational policies for healthcare and lifestyle decision-making among Australian aged care providers', (2019), vol 38(S2), *Australasian Journal on Ageing*, pp 90–7; Amanda Keeling, 'Supported decision making: The rights of pople with dementia'', (2016), vol 30(30), *Nursing Standard*, pp 38–44; Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton & Helen Radoslovich, 'Professionals' views and experiences in supporting decision-making involvement for people living with dementia', (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84–105.

29 Fauzia Knight, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, Kate Johnston-Ataata & Helen Herrman, 'Supported decision-making: the expectations held by people with experience of mental illness', (2018), vol 28(6), *Qualitative Health Research*, pp 1002–15; Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melbourne, 2017; Sophie Nunnelley, *Personal support networks in practice and theory: assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015; Lucy Knox, Jacinta Douglas & Christine Bigby '"I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents', (2016), vol 26(2), *Neuropsychological Rehabilitation*, pp 236–60; Alyson Norman, Sophie Moore, Rebecca Wotus, Mark Holloway & Jackie Dean, *Supported Decision Making: Brain injury case managers' experience of mental capacity and the Mental Capacity Act*, (Tehnical Report, February 2018) DOI: 10.13140/RG.2.2.35575.73128; Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton & Helen Radoslovich, 'Professionals' views and experiences in supporting decision-making involvement for people living with dementia', (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84–105.

30 Lucy Knox, Jacinta Douglas & Christine Bigby, ''The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI', (2015), vol 29(6), *Brain Injury*, pp 745–57; Lucy Knox, Jacinta Douglas & Christine Bigby, '"I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents', (2016), vol 26(2), *Neuropsychological Rehabilitation*, pp 236–60; Lucy Knox, Jacinta Douglas & Christine Bigby, '"I've never been a yes person": decision-making participation and self-conceptualization after severe traumatic brain injury', (2017), vol 39(22), *Disability and Rehabilitation*, pp 2250–60; Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": Views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587–608; Amanda Keeling, 'Supported decision making: the rights of pople with dementia'', (2016), vol 30(30), *Nursing Standard*, pp 38–44.

31 Christine Bigby & Jacinta Douglas, 'Examining complexities of support for decision making practice' in Ishita Khemka & Linda Hickson (ed), *Decision making by individuals with intellectual and developmental disabilities: Integrating research into practice*, Springer, 2021, pp 65–94.

32 Christine Bigby & Jacinta Douglas, 'Examining complexities of support for decision making practice' in Ishita Khemka & Linda Hickson (ed) *Decision making by individuals with intellectual and developmental disabilities: Integrating research into practice*, Springer, 2021, pp 65–94; Michelle Browning, Christine Bigby & Jacinta Douglas, 'A process of decision-making support: exploring supported decision-making practice in Canada', (2021), vol 46(2), *Journal of Intellectual & Developmental Disability*, pp 138–49.

33 See for example Craig Sinclair, Kate Gersbach, Michelle Hogan, Romola S Bucks, Kirsten A Auret, Josephine M Clayton, Meera Agar & Sue Kurrle, ‘How couples with dementia experience healthcare, lifestyle, and everyday decision-making’, (2018), vol 30(11), *International Psychogeriatrics*, pp 1639–47; Terry Carney & Shih-Ning Then, ‘Support for decision-making as people age with a cognitive impairment’ in Michelle Putnam & Christine Bigby (ed) *Handbook on Ageing with Disability*, Routledge, 2021, pp 186–95.

34 Lucy Knox, Jacinta Douglas & Christine Bigby, ‘‘The biggest thing is trying to live for two people’: Spousal experiences of supporting decision-making participation for partners with TBI’, (2015), vol 29(6), *Brain Injury*, pp 745–57; Craig Sinclair, Kate Gersbach, Michelle Hogan, Romola S Bucks, Kirsten A Auret, Josephine M Clayton, Meera Agar & Sue Kurrle, ‘How couples with dementia experience healthcare, lifestyle, and everyday decision-making’, (2018), vol 30(11), *International psychogeriatrics*, pp 1639–47; Deirdre Fetherstonhaugh, Jo-Anne Rayner & Laura Tarzia, ‘Hanging on to some autonomy in decision-making: how do spouse carers support this?’, (2019), vol 18(4), *Dementia: The International Journal of Social Research and Practice*, pp 1219–36; Jacinta Douglas, Christine Bigby, Lucy Knox & Michelle Browning, ‘Factors that underpin the delivery of effective decision-making support for people with cognitive disability’, (2015), vol 2(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 37-44; Geraldine Boyle, ‘Recognising the agency of people with dementia’, (2014), vol 29(7), *Disability & Society*, pp 1130–44.

35 Kritika Samsi & Jill Manthorpe, ‘Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers’, (2013), vol 25(6), *International Psychogeriatrics*, pp 949–61, 956; Craig Sinclair, Sue Field, Meredith Blake & Helen Radoslovich, ‘An examination of organisational policies for healthcare and lifestyle decision-making among Australian aged care providers’, (2019), vol 38(S2), *Australasian Journal on Ageing*, pp 90–7.

36 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A real bucket of worms”: Views of people living with dementia and family members on supported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587–608.

37 Lucy Knox, Jacinta Douglas & Christine Bigby, ‘Whose decision is it anyway? How clinicians support decision-making participation after acquired brain injury’, (2013), vol 35(22), *Disability and Rehabilitation*, pp 1926–32; Lucy Knox, Jacinta Douglas & Christine Bigby, ‘”I’ve never been a yes person”: Decision-making participation and self-conceptualization after severe traumatic brain injury’, (2017), vol 39(22), *Disability and Rehabilitation*, pp 2250–60; Lucy Knox, Jacinta Douglas & Christine Bigby, ‘”I won’t be around forever”: Understanding the decision-making experiences of adults with severe TBI and their parents’, (2016), vol 26(2), *Neuropsychological Rehabilitation*, pp 236–60; Alyson Norman, Sophie Moore, Rebecca Wotus, Mark Holloway & Jackie Dean, *Supported decision making: brain injury case managers’ experience of mental capacity and the mental capacity act*, (Technical Report, February 2018) DOI: 10.13140/RG.2.2.35575.73128

38 Paul Webb, Gavin Davidson, Rosalie Edge, David Falls, Fionnuala Keenan, Berni Kelly, Aisling McLaughlin, Lorna Montgomery, Christine Mulvenna, Barbara Norris, Aine Owens & Rebecca Shea Irvine, ‘Service users’ experiences and views of support for decision-making’, (2020), vol 28(4), *Health & Social Care in the Community*, pp 1282–91; Bernadette Curryer, Angela Dew, Roger J Stancliffe & Michele Y Wiese, ‘Adults with intellectual disability: choice and control in the context of family’ in Roger A Stancliffe, Michale L Wehmeyer, Karrie A Shogren & Brian H Abery (ed) *Choice, preference and disability: Promoting self-determination across the lifespan*, Springer, 2020, pp 283–302; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences’, (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481

39 Fauzia Knight, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, Kate Johnston-Ataata & Helen Herrman, ‘Supported decision-making: the expectations held by people with experience of mental illness’, (2018), vol 28(6), *Qualitative Health Research*, pp 1002–15; Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen

Herrman, ‘Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners’, (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826–33; Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melbourne, 2017.

40 Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton & Helen Radoslovich, ‘Professionals’ views and experiences in supporting decision-making involvement for people living with dementia’, (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84–105; Kritika Samsi & Jill Manthorpe, ‘Everyday decision-making in dementia: Findings from a longitudinal interview study of people with dementia and family carers’, (2013), vol 25(6), *International Psychogeriatrics*, pp 949–61.

41 Nandini Devi, Birgit Prodinger, Andrew Pennycott, Roja Sooben & Jerome Bickenbach, ‘Investigating supported decision-making for persons with mild to moderate intellectual disability using institutional ethnography’, (2020), vol 17(2), *Journal of Policy and Practice in Intellectual Disabilities*, pp 143–56; Christine Bigby, Mary Whiteside & Jacinta Douglas, ‘Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services’, (2019), vol 44 (4), *Journal of Intellectual & Developmental Disability*, pp 396-409; Lucy Knox, Jacinta Douglas & Christine Bigby, ‘‘The biggest thing is trying to live for two people’: Spousal experiences of supporting decision-making participation for partners with TBI’, (2015), vol 29(6), *Brain Injury*, pp 745–57.

42 Giles Newton-Howes & Sarah Gordon, ‘Who controls your future: the Convention on the Rights of Persons with Disabilities from a service user focused perspective’, (2020), vol 54 (2), *Australian and New Zealand Journal of Psychiatry*, pp 134–7; James Cooney, Michael Daly, Giles Newton-Howes, Kris Gledhill & Sarah Gordon, ‘Making the Convention on the Rights of Persons with Disabilities real: our word is our bond’, (2021), vol 134(1534), *The New Zealand Medical Journal (Online)*, pp 8–10; Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, ‘Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners’, (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826–33.

43 Lucy Knox, Jacinta Douglas & Christine Bigby, ‘Becoming a decision-making supporter for someone with acquired cognitive disability following traumatic brain injury’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 12–21.

44 Christine Bigby, Jacinta Douglas, Terry Carney, Shih-Ning Then, Illan Wiesel & Elizabeth Smith, ‘Delivering decision making support to people with cognitive disability - what has been learned from pilot programs in australia from 2010 to 2015’, (2017), vol 52(3), *Australian Journal of Social Issues*, pp 222–40.

45 Jacinta Douglas & Christine Bigby, ‘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’, (2020), vol 42(3), *Disability and Rehabilitation*, pp 434–41.

46 See, for example, Tal Araten-Bergman & Christine Bigby, ‘Forming and supporting circles of support for people with intellectual disabilities – a comparative case analysis’, (2021), *Journal of Intellectual & Developmental Disability*, https://doi.org/10.3109/13668250.2021.1961049; Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015.

47 Christine Bigby, Jacinta Douglas & Lisa Hamilton, *Overview of Literature About Enabling Risk for People with Cognitive Disabilities In Context of Disability Support Services*, Living with Disability Research Centre, La Trobe University, 2018.

48 Robert Perske, ‘The dignity of risk’, in W Wolfensberger et al (ed) *The principle of normalization in human services*, National Institute of Mental Retardation, 1972, pp 194–200; see also Piers Gooding, ‘Supported decision-making: a rights-based disability concept and its implications for mental health law’, (2013), vol 20(3), *Psychiatry, Psychology and Law*, pp 431–451.

49 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, 2014, p 53.

50 In the case of adults with mental health conditions, concerns were expressed if Community Treatment Orders were not available due to the risk of harm: Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, 'Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners', (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826–33; Lisa Brophy, Renata Kokanovic, Jacinthe Flore, Bernadette McSherry & Helen Herrman, 'Community treatment orders and supported decision-making', (2019), vol 10, *Frontiers in Psychiatry*, 414:1–12; but also more generally Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, 'Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities' (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174.

51 Eleonore Batteux, Eamonn Ferguson & Richard J Tunney, 'Do we make decisions for other people based on our predictions of their preferences? Evidence from financial and medical scenarios involving risk', (2020), vol 26(2), *Thinking & Reasoning*, pp 188–217.

52 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social &Cultural Geography*, DOI: 10.1080/14649365.2020.1829689; Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, 'Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities' (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, 'Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences', (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481; Meredith Stone, Renata Kokanovic, Felicity Callard & Alex F Broom, 'Estranged relations: coercion and care in narratives of supported decision-making in mental healthcare', (2020), vol 46(1), *Medical Humanities*, pp 62–72.

53 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social &Cultural Geography*, DOI: 10.1080/14649365.2020.1829689; Craig Sinclair, Sue Field, Meredith Blake & Helen Radoslovich, 'An examination of organisational policies for healthcare and lifestyle decision-making among Australian aged care providers', (2019), vol 38(S2), *Australasian Journal on Ageing*, pp 90–7

54 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social &Cultural Geography*, DOI: 10.1080/14649365.2020.1829689; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, 'Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences', (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481; see also in the context of moving to substitute decision-making: Deirdre Fetherstonhaugh, Linda McAuliffe, Christopher Shanley, Michael Bauer & Elizabeth Beattie, '"Did I make the right decision?": The difficult and unpredictable journey of being a surrogate decision maker for a person living with dementia', (2019), vol 18(5), *Dementia (London, England)*, pp 1601-14; Bernadette Curryer, Roger J Stancliffe & Angela Dew, 'Self-determination: adults with intellectual disability and their family', (2015), vol 40(4), *Journal of intellectual & Developmental Disability*, pp 394–9; Bernadette Curryer, Angela Dew, Roger J Stancliffe & Michele Y Wiese, 'Adults with intellectual disability: choice and control in the context of family' in Roger A Stancliffe, Michale L Wehmeyer, Karrie A Shogren & Brian H Abery (ed) *Choice, preference and disability: Promoting self-determination across the lifespan*, Springer, 2020, pp 283-302.

55 Kristin Booth Glen, 'Introducing a new human right: learning from others, bringing legal capacity home', (2018), vol 49(3), *Columbia Human Rights Law Review*, pp 1–96; Wayne Martin, Sabine Michalowski, Jill Stavert, Adrian Ward, A Ruck Keene, Colin Caughey, Alision Hempsey & Rebecca McGregor, *Three jurisdictions report: towards compliance with CRPD article 12 in*

capacity/incapacity Legislation across the UK, Essex Autonomy Project, 2016; Anne Plumb, 'UN Convention on the Rights of Persons with Disabilities: out of the frying pan into the fire? Mental health service users and survivors aligning with the disability movement' in Helen Spandler, Jill Anderson & Bob Sapey (ed) *Madness, Distress and the Politics of Disablement,* Bristol University Press, 2015, pp 183-98; Brigit Merfin-Veitch, *Exploring article 12 of the United Nations Convenion on the Rights of Persons with Disabilities: an integrative literature review,* Donald Beasley Institute, 2016, pp 27–8.

56 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014); see discussion in: Anna Arstein-Kerslake, 'An empowering dependency: exploring support for the exercise of legal capacity', (2016), vol 18, *Scandinavian Journal of Disability Research,* pp 77–92.

57 Paul Skowron, 'Giving substance to 'the best interpretation of will and preferences'', (2019), vol 62, *International Journal of Law and Psychiatry*, pp 125–34; Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel, Jacinta Douglas & Elizabeth Smith, 'Realising 'Will, preferences and rights': reconciling differences on best practice support for decision-making?' (2019), vol 28(4), *Griffith Law Review*, pp 357–79; George Szmukler, ''Capacity', 'best interests', 'will and preferences' and the UN Convention on the Rights of Persons with Disabilities', (2019), vol 18(1), *World Psychiatry*, pp 34–41.

58 Nandini Devi, 'Supported decision-making and personal autonomy for persons with intellectual disabilities: article 12 of the UN Convention on the Rights of Persons with Disabilities', (2013), vol 41(4), *The Journal of Law, Medicine & Ethics*, pp 792–806, 801; see also: Jeanne Snelling & Alison Douglass, 'Legal capacity and supported decision-making' in Iris Reuvecamp & John Dawson (ed) *Mental Capacity Law in New Zealand*, Thomson Reuters, 2019, pp 163–77.

59 Nandini Devi, 'Supported decision-making and personal autonomy for persons with intellectual disabilities: article 12 of the UN Convention on the Rights of Persons with Disabilities', (2013), vol 41(4), *The Journal of Law, Medicine & Ethics*, pp 792–806.

60 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, (2014).

61 Nandini Devi, 'Supported decision-making and personal autonomy for persons with intellectual disabilities: article 12 of the UN Convention on the Rights of Persons with Disabilities', (2013), vol 41(4), *The Journal of Law, Medicine & Ethics*, pp 792–806.

62 Terry Carney, 'Searching for workable alternatives to guardianship for vulnerable populations?', (2015), vol 1(1), *Ethics, Medicine and Public Health*, pp 113–19; Terry Carney, 'Supported decision-making for people with cognitive ipairments: An Australian perspective?', (2015), vol 4, *Laws*, pp 37–59.

63 Jane Tracy, 'Supporting Nick to make decisions: n exploration of ways to promote choice and control', (2015), vol 2(1), *Research and practice in intellectual and developmental disabilities*, pp 29–36, 33.

64 Jane Tracy, 'Supporting Nick to make decisions: an exploration of ways to promote choice and control', (2015), vol 2(1), *Research and practice in intellectual and developmental disabilities*, pp 29–36.

65 Jane Tracy, 'Supporting Nick to make decisions: An exploration of ways to promote choice and control', (2015), vol 2(1), *Research and practice in intellectual and developmental disabilities*, pp 29–36, 33–35.

66 Joanne Watson, 'Assumptions of decision-making capacity: the role supporter attitudes play in the realisation of article 12 for people with severe or profound intellectual disability', (2016), vol 5(6), *Laws*, doi:10.3390/laws5010006

67 Joanne Watson, Hille Voss & Melissa J Bloomer, 'Placing the preferences of people with profound intellectual and multiple disabilities at the center of end-of-life decision making through storytelling', (2019), vol 44(4), *Research and Practice for Persons with Severe Disabilities*, pp 267–79; see also: Joanne Watson, Erin Wilson & Nick Hagiliassis, 'Supporting end of life decision making: case studies of relational closeness in supported decision making for people with severe or profound intellectual disability', (2017), vol 30(6), *Journal of Applied Research in Intellectual Disabilities*, pp 1022–34.

68 Joanne Watson, Hille Voss & Melissa J Bloomer, ‘Placing the preferences of people with profound intellectual and multiple disabilities at the center of end-of-life decision making through storytelling’, (2019), vol 44(4), *Research and Practice for Persons with Severe Disabilities*, pp 267–79, 272.

69 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘“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’, (2021), *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623

70 Bernadette Curryer, Roger J Stancliffe, Michele Y Wiese & Angela Dew, ‘The experience of mothers supporting self-determination of adult sons and daughters with intellectual disability’, (2020), vol 33(3), *Journal of Applied Research in Intellectual Disabilities*, pp 373–85; Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174Michelle Jennett Browning, ‘Developing an understanding of supported decision-making practice in Canada: The experiences of people with intellectual disabilities and their supporter’, PhD Thesis, La Trobe University, 2018, pp iii; Christine Bigby & Jacinta Douglas, ‘Examining the complexities of the practice of support for decision making’ in Ishita Khemka & Linda Hickson (ed) *Decision making by individuals with intellectual and Developmental Disabilities: integrating research into Practice*, Springer, 2021, pp 65–94.

71 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174; Lucy Knox, Jacinta Douglas & Christine Bigby, ‘Becoming a decision-making supporter for someone with acquired cognitive disability following traumatic brain injury’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 12–21; Lucy Knox, Jacinta Douglas & Christine Bigby, ‘”I won’t be around forever”: Understanding the decision-making experiences of adults with severe TBI and their parents’, (2016), vol 26(2), *Neuropsychological Rehabilitation*, pp 236–60; Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A real bucket of worms”: Views of people living with dementia and family members on supported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587–608; Alessandro Bosco, Justine Schneider, Donna Maria Coleston-Shields, Kaanthan Jawahar, Paul Higgs & Martin Orrell, ‘Agency in dementia care: systematic review and meta-ethnography’, (2019), vol 31(5), *International Psychogeriatrics*, pp 627–62; Kritika Samsi & Jill Manthorpe, ‘Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers’, (2013), vol 25(6), *International Psychogeriatrics*, pp 949–61.

72 Lucy Knox, Jacinta Douglas & Christine Bigby, ‘”I won’t be around forever”: understanding the decision-making experiences of adults with severe TBI and their parents’, (2016), vol 26(2), *Neuropsychological Rehabilitation*, pp 236–60; Lucy Knox, Jacinta Douglas & Christine Bigby, ‘Becoming a decision-making supporter for someone with acquired cognitive disability following traumatic brain injury’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 12–21; Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174; see also Shirli Werner & Rachel Chabany, ‘Guardianship law versus supported decision-making policies: Pperceptions of persons with intellectual or psychiatric disabilities and parents’, (2016), vol 86(5), *American Journal of Orthopsychiatry*, pp 486–99; The Arc of Northern Virginia (The Arc) & The Burton Blatt Institute at Syracuse University (BBI), *“I learned that I have a voice in my future”: Summary, Findings, and Recommendations of the Virginia Supported Decision-Making Pilot Project*’, http://www.supporteddecisionmaking.org/sdm-va-report-findings-2021.

73 Meredith Stone, Renata Kokanovic, Felicity Callard & Alex F Broom, ‘Estranged relations: coercion and care in narratives of supported decision-making in mental healthcare’, (2020), vol 46(1), *Medical Humanities*, pp 62–72.

74 Megan S Wright, ‘Dementia, healthcare decision mking, and disability law’, (2019), vol 47(S 4), *The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics*, pp 25–33; George Szmukler, ‘’Capacity’, ‘best interests’, ‘will and preferences’ and the UN Convention on the Rights of Persons with Disabilities’, (2019), vol 18(1), *World Psychiatry*, pp 34–41; John Phillips & David Wendler, ‘Clarifying substituted judgement: the endorsed life approach: Table 1’, (2015), vol 41(9), *Journal of Medical Ethics*, pp 723–30; Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, ‘The temporalities of supported decision-making by people with cognitive disability,’ (2020), *Social &Cultural Geography*, DOI: 10.1080/14649365.2020.1829689; Megan Wright, ‘Dementia, cognitive transformation, and supported decision making’, (2020), vol 20(8), *American Journal of Bioethics*, pp 88–90; Terry Carney, ‘Combating elder abuse: any role for supported-decision-making, adult guardianship or other laws?’ in Mala Kapur Shankardass (ed) *Combating Elder Abuse in Australia and India*, Nova Science, 2020, pp 265–87; Anita Smith & Danny Sullivan, ‘A new ball game: the United Nations Convention on the Rights of Persons with Disabilities and assumptions in care for people with dementia’, (2012), vol 20(1), *Journal of Law and Medicine,* pp 28-34; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel (2021): ‘“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’, *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623

75 Fauzia Knight, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, Kate Johnston-Ataata & Helen Herrman, ‘Supported decision-making: the expectations held by people with experience of mental illness’, (2018), vol 28(6), *Qualitative Health Research*, pp 1002–15, 1011.

76 Meredith Blake, Olivia Nicole Doray & Craig Sinclair, ‘Advance care planning for people with dementia in Western Australia: An examination of the fit between the law and practice’, (2018), vol 25(2), *Psychiatry,Ppsychology, and Law*, pp 197–218; Jürgen Schmitten, Ralf J Jox, Michael Pentzek & Georg Marckmann, ‘Advance care planning by proxy in German nursing homes: descriptive analysis and policy implications’, (2021), vol 69(8), *Journal of the American Geriatrics Society (JAGS)*, pp 2122–31.

77 Jeremy Dixon, Sarah Donnelly, Jim Campbell & Judy Laing, ‘Safeguarding people living with dementia: how social workers can use supported decision-making strategies to support the human rights of individuals during adult safeguarding enquiries’, (2021), *The British Journal of Social Work*, pp 1–18; Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, ‘The temporalities of supported decision-making by people with cognitive disability,’ (2020), *Social &Cultural Geography*, DOI: 10.1080/14649365.2029689

78 Jeremy Dixon, Sarah Donnelly, Jim Campbell & Judy Laing, ‘Safeguarding people living with dementia: how social workers can use supported decision-making strategies to support the human rights of individuals during adult safeguarding enquiries’, (2021), *The British Journal of Social Work*, pp 1–18; Jacinta Douglas & Christine Bigby, ‘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’, (2020), vol 42(3), *Disability and Rehabilitation*, pp 434–41; Craig Sinclair, Susan Kurrle, Sue Field, Meera Agar, Kathy Williams, Romola Bucks, Josephine Clayton, Cameron Stewart, Meredith Blake, Kirsten Auret, Meredith Gresham, Angelilta Martini & Helen Radoslovich, *Supported Decision-Making in Dementia Care: Final Project Report*, NHMRC Cognitive Decline Partnership Centre, 2019; Amanda Keeling, ‘Supported decision making: The rights of pople with dementia’’, (2016), vol 30(30), *Nursing Standard*, pp 38-44.

79 Paul Webb, Gavin Davidson, Rosalie Edge, David Falls, Fionnuala Keenan, Berni Kelly, Aisling McLaughlin, Lorna Montgomery, Christine Mulvenna, Barbara Norris, Aine Owens & Rebecca Shea Irvine, ‘Key components of supporting and assessing decision making ability’, (2020), vol 72, *International Journal of Law and Psychiatry*, 101613.

80 Karen Strickland, Kasia Bail, Sarah Cope, Murray Turner & Cameron Moss, ‘Supported Decision-making to assist older persons experiencing elder abuse: an integrative review’, (2021), vol 28(4), *Collegian*, pp 447–55; Craig Sinclair, Susan Kurrle, Sue Field, Meera Agar, Kathy Williams, Romola Bucks, Josephine Clayton, Cameron Stewart, Meredith Blake, Kirsten Auret, Meredith Gresham, Angelilta Martini & Helen Radoslovich, *Supported Decision-Making in Dementia Care: Final Project Report*, NHMRC Cognitive Decline Partnership Centre, 2019; Niki Edwards, Julie King, Sara Hair & Kate Walton, *Articulation of a Best Practice Model of Guardianship Advocacy*

Services: For Older People and People with Cognitive Disability at risk of Abuse and Neglect, (Technical Report, 2019); Terry Carney, ‘Supported decision-making in Australia: meeting the challenge of moving from capacity to capacity-building?’, (2017), vol 35, *Law in Context*, pp 44–63; Lucy Knox, Jacinta Douglas & Christine Bigby, ‘”I’ve never been a yes person”: Decision-making participation and self-conceptualization after severe traumatic brain injury’, (2017), vol 39(22), *Disability and Rehabilitation*, pp 2250–60; Lucy Knox, Jacinta Douglas & Christine Bigby, ‘”I won’t be around forever”: Understanding the decision-making experiences of adults with severe TBI and their parents’, (2016), vol 26(2), *Neuropsychological Rehabilitation*, pp 236–60.

81 M McCarron, P McCallion, E Reilly & N Mulryan, ‘A prospective 14-year longitudinal follow-up of dementia in persons with Down syndrome: Dementia follow-up’, (2014), vol 58(1), *Journal of Intellectual Disability Research*; Terry Carney & Shih-Ning Then, ‘Support for decision-making as people age with a cognitive impairment’ in Michelle Putnam & Christine Bigby (ed) *Handbook on Ageing with Disability*, Routledge, 2021, pp 186–95.

82 Anita Gjermestad, Laila Luteberget, Turid Midjo & Aud Elisabeth Witsø, ‘Everyday life of persons with intellectual disability living in residential settings: a systematic review of qualitative studies’, (2017), vol 32(2), *Disability & Society*, pp 213-32.

83 Tim Stainton, ‘Supported decision-making in Canada: principles, policy, and practice’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 1–11; Michelle Browning, Christine Bigby & Jacinta Douglas, ‘A process of decision-making support: exploring supported decision-making practice in Canada’, (2021), vol 46(2), *Journal of Intellectual & Developmental Disability*, pp 138–49.

84 Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel, Jacinta Douglas & Elizabeth Smith, ‘Realising ‘will, references and rights’: reconciling differences on best practice support for decision-making?’ (2019), vol 28(4), *Griffith Law Review*, pp 357–79; see also Patrick McKearney, ‘Challenging care: Professionally not knowing what good care is’, (2020), vol 45(2), *Anthropology and Humanism*, pp 223–32.

85 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, ‘The temporalities of supported decision-making by people with cognitive disability,’ (2020), *Social &Cultural Geography* DOI: 10.1080/14649365.2020.1829689

86 Terry Carney & Fleur Beaupert, ‘Public and private bricolage: challenges balancing law, services and civil society in advancing the CRPD supported decision making’, (2013), vol 36(1), *University of New South Wales Law Journal*, pp 175–201, 193.

87 Bernadette Curryer, Roger J Stancliffe & Angela Dew, ‘Self-determination: adults with intellectual disability and their family’, (2015), vol 40(4), *Journal of intellectual & developmental disability*, pp 394–9; Bernadette Curryer, Roger J Stancliffe, Michele Y Wiese & Angela Dew, ‘The experience of mothers supporting self-determination of adult sons and daughters with intellectual disability’, (2020), vol 33(3), *Journal of applied research in intellectual disabilities*, pp 373–85; Whitney D Taylor, Virginie Cobigo & Hélène Ouellette-Kuntz, ‘A family systems perspective on supporting self-determination in young adults with intellectual and developmental disabilities’, (2019), vol 32(5), *Journal of Applied Research in Intellectual Disabilities*, pp 1116–28; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences’, (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481

88 Christine Bigby, Mary Whiteside & Jacinta Douglas, *Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas*, Living with Disability Research Centre, La Trobe University, 2015.

89 Christine Bigby, Mary Whiteside & Jacinta Douglas, *Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas*, Living with Disability Research Centre, La Trobe University, 2015.

90 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.

91 Lucy Series, Anna Arstein-Kerslake & Elizabeth Kamunida, ‘Legal capacity: a global analysis of reform trends’ in Peter Blanck & Eilionoir Flynn (ed) *Routledge Handbook of Disability Law and Human Rights* Routledge, 2016, pp 137–55.

92 Commissioner for Human Rights (Council of Europe), *Who Gets to Decide? Right to legal capacity for persons with intellectual and psychosocial disabilities*, (2012), pp 20; Terry Carney, ‘Participation and service access rights for people with intellectual disability: a role for law?’, (2013), vol 38(1), *Journal of Intellectual & Developmental Disability*, pp 59-59; Terry Carney, ‘Prioritising supported decision-making: running on empty or a basis for glacial-to-steady progress?’, (2017), vol 6(4), *Laws*, pp 18–27; Terry Carney, ‘Supported ecision-making in Australia: meeting the challenge of moving from capacity to capacity-building?’, (2017), vol 35, *Law in Context*, pp 44-63.

93 Nandini Devi, Birgit Prodinger, Andrew Pennycott, Roja Sooben & Jerome Bickenbach, ‘Investigating supported decision-making for persons with mild to moderate intellectual disability using institutional ethnography’, (2020), vol 17(2), *Journal of Policy and Practice in Intellectual Disabilities*, pp 143-56; Michelle Jennett Browning, ‘Developing an understanding of supported decision-making practice in Canada: The experiences of people with intellectual disabilities and their supporter’, PhD Thesis, La Trobe University, 2018, iii.; Michelle Browning, Christine Bigby & Jacinta Douglas, ‘A process of decision-making support: exploring supported decision-making practice in Canada’, (2021), vol 46(2), *Journal of Intellectual & Developmental Disability*, pp 138-49.

94 Michelle Jennett Browning, ‘Developing an understanding of supported decision-making practice in Canada: The experiences of people with intellectual disabilities and their supporter’, PhD Thesis, La Trobe University, 2018, 176-77; Christine Bigby, Mary Whiteside & Jacinta Douglas, ‘Providing support for decision making to adults with intellectual disability: perspectives of family members and workers in disability support services’, (2019), vol 44(4), *Journal of Intellectual & Developmental Disability*, pp 396-409.

95 Brenda Burgen, ‘Reflections on the Victorian Office of the Public Advocate supported decision-making pilot project’, (2016), vol 3(2), *Research and practice in intellectual disabilities*, pp 165-8; Office of the Public Advocate (Vic) & VALID, *Volunteer programs of support for decision-making: lessons and recommendations from the OVAL project*, VALID and Office of the Public Advocate, 2017; Bizchut (The Israeli Human Rights Center for People with Disabilities), *Supported Decision-Making Service for Persons with Disabilities: Service Model*, Bizchut, 2016; there is also some evidence of success in relation to the Personal Ombudsman model described at Section8.4.1 *Sweden’s Personal Ombudsman (PO) Skåne independent advocacy.*

96 Michelle Browning, Christine Bigby & Jacinta Douglas, ‘A process of decision-making support: Exploring supported decision-making practice in Canada’, (2021), vol 46(2), *Journal of Intellectual & Developmental Disability*, pp 138-49.

97 Christine Bigby, Ruth Webber & Barbara Bower, ‘Sibling roles in the lives of older group home residents with intellectual disability: Working with staff to safeguard wellbeing’, (2015), vol 68, *Australian Social Work*, pp 453-68; cf Anna M Brady, Meghan M Burke, Trenton Landon & Kathleen Oertle, ‘Siblings of adults with intellectual and developmental disabilities: their knowledge and perspectives on guardianship and its alternatives’, (2019), vol 32(5), *Journal of Applied Research in Intellectual Disabilities*, pp 1078-87.

98 Bernadette Curryer, Angela Dew, Roger J Stancliffe & Michele Y Wiese, ‘Adults with intellectual disability: choice and control in the context of family’ in Roger A Stancliffe, Michale L Wehmeyer, Karrie A Shogren & Brian H Abery (ed) *Choice, preference and disability: Promoting self-determination across the lifespan*, Springer, 2020, pp 283-302; Bernadette Curryer, Roger J Stancliffe & Angela Dew, ‘Self-determination: adults with intellectual disability and their family’, (2015), vol 40(4), *Journal of Intellectual & Developmental Disability,* pp 394-9.

99 Nandini Devi, Birgit Prodinger, Andrew Pennycott, Roja Sooben & Jerome Bickenbach, ‘Investigating supported decision-making for persons with mild to moderate intellectual disability using institutional ethnography’, (2020), vol 17(2), *Journal of Policy and Practice in Intellectual Disabilities*, pp 143-56.

100 Christine Bigby, Mary Whiteside & Jacinta Douglas, ‘Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services’, (2019), vol 44(4), *Journal of Intellectual & Developmental Disability*, pp 396-409

101 Nandini Devi, Birgit Prodinger, Andrew Pennycott, Roja Sooben & Jerome Bickenbach, ‘Investigating supported decision-making for persons with mild to moderate intellectual disability using institutional ethnography’, (2020), vol 17(2), *Journal of Policy and Practice in Intellectual Disabilities*, pp 143-56, 152.

102 William F Sullivan & John Heng, ‘Supporting adults with intellectual and developmental disabilities to participate in health care decision making’, (2018), vol 64(Suppl 2), *Canadian Family Physician Medecin de Famille Canadien*, pp S32-S36.

103 Michelle Jennett Browning, ‘Developing an understanding of supported decision-making practice in Canada: The experiences of people with intellectual disabilities and their supporter’, PhD Thesis, La Trobe University, 2018, p 174; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences’, (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481; Michelle Browning, Christine Bigby & Jacinta Douglas, ‘A process of decision-making support: exploring supported decision-making practice in Canada’, (2021), vol 46(2), *Journal of Intellectual & Developmental Disability*, pp 138-49.

104 Christine Bigby, Mary Whiteside & Jacinta Douglas, ‘Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services’, (2019), vol 44(4), *Journal of Intellectual & Developmental Disability*, pp 396-409.

105 Christine Bigby, Mary Whiteside & Jacinta Douglas, ‘Providing support for decision making to adults with intellectual disability: perspectives of family members and workers in disability support services’, (2019), vol 44(4), *Journal of Intellectual & Developmental Disability*, pp 396-409.

106 Clarissa Kripke, ‘Adults with developmental disabilities: A Comprehensive Approach to Medical Care’, (2018), vol 97(10), *American Family Physician*, pp 649-56; Rebecca Bailey, Paul Willner & Simon Dymond, ‘A visual aid to decision-making for people with intellectual disabilities’, (2011), vol 32(1), *Research in Developmental Disabilities*, pp 37-46.

107 Michelle Jennett Browning, ‘Developing an understanding of supported decision-making practice in Canada: The experiences of people with intellectual disabilities and their supporter’, PhD Thesis, La Trobe University, 2018198.

108 Bernadette Curryer, Roger J Stancliffe, Michele Y Wiese & Angela Dew, ‘The experience of mothers supporting self-determination of adult sons and daughters with intellectual disability’, (2020), vol 33(3), *Journal of Applied Research in Intellectual Disabilities*, pp 373-85.

109 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174; Michelle Jennett Browning, ‘Developing an understanding of supported decision-making practice in Canada: the experiences of people with intellectual disabilities and their supporter’, PhD Thesis, La Trobe University, 2018, iii; Christine Bigby & Jacinta Douglas, ‘Examining the complexities of support for decision-making practice’ in Ishita Khemka & Linda Hickson (ed) *Decision making by individuals with intellectual and developmental disabilities: Integrating research into practice*, Springer, 2021, pp 65-94,

110 Shirli Werner & Rachel Chabany, ‘Guardianship law versus supported decision-making policies: Perceptions of persons with intellectual or psychiatric disabilities and parents’, (2016), vol 86(5), *American Journal of Orthopsychiatry*, pp 486-99, 493.

111 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences’, (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481; Christine Bigby & Jacinta Douglas, ‘Examining the complexities of support for decision-making practice’ in Ishita Khemka & Linda Hickson (ed) *Decision making by individuals with intellectual and developmental disabilities: Integrating research into practice*, Springer, 2021, pp 65-94; Whitney D Taylor, Virginie Cobigo & Hélène Ouellette-Kuntz, ‘A family systems perspective on

supporting self-determination in young adults with intellectual and developmental disabilities', (2019), vol 32(5), *Journal of Applied Research in Intellectual Disabilities*, pp 1116-28.

112 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, 'Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences', (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481; Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, 'Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities' (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174

113 IHC New Zealand, 'Research report: What does helpful supported decision-making look like to people with intellectual disabilities? (20xx) https://ihc.org.nz/sites/default/files/IHC%20A4%20Booklet%20Web.pdf

114 Rosie Harding & Taşcıoğlu Ezgi,'Supported decision-making from theory to practice: Implementing the right to enjoy legal capacity', (2018), vol 8(2), *Societies (Basel, Switzerland)*, 14, doi:10.3390/soc8020025

115 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social &Cultural Geography*, DOI: 10.1080/14649365.2020.1829689

116 Canadian Centre for Elder Law, *Study Paper on Inclusive Investing: Respecting the Rights of Vulnerable Investors through Supported Decision-Making*, 2021.

117 See, for example, Disability Voices United, *With Support and without the Court: Supported Decision-Making Handbook for Parents of Adults with Developmental Disabilities in California*, 2020, pp 24-33.

118 See, for example, The Arc of Arizona, *Supported Decision Making and You: Your Curriculum Guide on Supported Decision Making*, undated, p 5.

119 Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015.

120 Tal Araten-Bergman & Christine Bigby, 'Forming and supporting circles of support for people with intellectual disabilities – a comparative case analysis', (2021), *Journal of Intellectual & Developmental Disability* https://doi.org/10.3109/13668250.2021.1961049

121 See for example: Joanne Watson, Erin Wilson & Nick Hagiliassis, 'Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability', (2017), vol 30 (6), *Journal of Applied Research in Intellectual Disabilities*, pp 1022-34; Tal Araten-Bergman & Christine Bigby, 'Forming and supporting circles of support for people with intellectual disabilities – a comparative case analysis', (2021), *Journal of Intellectual & Developmental Disability* https://doi.org/10.3109/13668250.2021.1961049

122 Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015, pp 98-9.

123 Tal Araten-Bergman & Christine Bigby, 'Forming and supporting circles of support for people with intellectual disabilities – a comparative case analysis', (2021), *Journal of Intellectual & Developmental Disability*, https://doi.org/10.3109/13668250.2021.1961049

124 World Health Organization, *Supported decision-making and advance planning: WHO QualityRights Specialized training: course guide*, (2019) (WHO/MSD/MHP/17.8) - https://www.who.int/publications/i/item/9789241516761

125 World Health Organization, *Supported decision-making and advance planning: WHO QualityRights Specialized training: course guide*, (2019) (WHO/MSD/MHP/17.8) - https://www.who.int/publications/i/item/9789241516761

126 See Michelle Funk, Natalie Drew Bold, Joana Ansong, Daniel Chisholm, Melita Murko, Joyce Nato, Sally-Ann Ohene, Jasmine Vergara & Edwina Zoghbi, 'Strategies to achieve a rights-based approach through WHO QualityRights' in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 44-59; Soumitra Pathare & Arjun Kapoor, 'Decisional autonomy and India's Mental Healthcare Act, 2017: a comment on emerging jurisprudence' in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 155-70.

127 Jacinta Douglas & Christine Bigby, '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', (2020), vol 42(3), *Disability and Rehabilitation*, pp 434-41.

128 Jacinta Douglas & Christine Bigby, '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', (2020), vol 42(3), *Disability and Rehabilitation*, pp 434-41.

129 Jacinta Douglas & Christine Bigby, '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', (2020), vol 42(3), *Disability and Rehabilitation*, pp 434-41; Christine Bigby & Jacinta Douglas, 'Supported Decision Making' in Roger J Stancliffe, Michael L Wehmeyer, Karrie A Shogren & Brian H Abery (ed) *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan*, Springer International Publishing, 2020, pp 45-66.

130 Christine Bigby, Mary Whiteside & Jacinta Douglas, *Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas*, (Living with Disability Research Centre, La Trobe University, 2015, 7; Jacinta Douglas, Christine Bigby, Lucy Knox & Michelle Browning, 'Factors that underpin the Delivery of Effective Decision-making Support for People with Cognitive Disability', (2015), vol 2(1), *Research and Practice in Intellectual and Developmental Disabilities*, DOI: 10.3109/13668250.2021.1954481; Jacinta Douglas & Christine Bigby, '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', (2020), vol 42(3), *Disability and Rehabilitation*, pp 434-41.

131 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social & Cultural Geography*, DOI: 10.1080/14649365.2020.1829689; Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, 'Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities' (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174Christine Bigby, Jacinta Douglas, Ellizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, 'Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences', (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481

132 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, '"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', (2021), *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623

133 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, '"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', (2021), *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623

134 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, '"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', (2021), *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623

135 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, '"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', (2021), *Disability and Rehabilitation*; see also Terry Carney, Christine Bigby, Shih-Ning Then, Elizabeth Smith, Ilan Wiesel & Jacinta Douglas, 'Paternalism to empowerment: all in the eye of the beholder?', (2021), *Disability and Society*, DOI: 10.1080/09687599.2021.1941781

136 Christine Bigby & Jacinta Douglas, 'Examining complexities of support for decision making practice' in Ishita Khemka & Linda Hickson (ed) *Decision making by individuals with intellectual and developmental disabilities: Integrating research into practice*, Springer, 2021, pp 65-94.

137 Christine Bigby, Jacinta Douglas & Elizabeth Smith, *Considering human rights in decision making: Evaluation of the introduction of structured decision making framework in the Public Trustee Queensland*, Living with Disability Research Centre, La Trobe University, Bundoora, Vic, 2021;

Jacinta Douglas, Christine Bigby & Elizabeth Smith, *Building capability to support client decision making: TAC Project No. T005*, Living with Disability Research Centre, La Trobe University, 2020.

138 Lucy Knox, Jacinta Douglas & Christine Bigby, ''The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI', (2015), vol 29(6), *Brain Injury*, pp 745-57, 745.

139 Lucy Knox, Jacinta Douglas & Christine Bigby, ''The biggest thing is trying to live for two people': spousal experiences of supporting decision-making participation for partners with TBI', (2015), vol 29(6), *Brain Injury*, pp 745-57.

140 See for example, George Szmukler, ''Capacity', 'best interests', 'will and preferences' and the UN Convention on the Rights of Persons with Disabilities', (2019), vol 18(1), *World Psychiatry*, pp 34-41; John Phillips & David Wendler, 'Clarifying substituted judgement: the endorsed life approach: Table 1', (2015), vol 41(9), *Journal of Medical Ethics*, pp 723-30.

141 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social &Cultural Geography*, p 11 DOI: 10.1080/14649365.2020.1829689

142 Eg Rosie Harding & Taşcıoğlu Ezgi,'Supported decision-making from theory to practice:iImplementing the right to enjoy legal capacity', (2018), vol 8(2), *Societies (Basel, Switzerland)*, doi:10.3390/soc8020025; Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social &Cultural Geography*, DOI: 10.1080/14649365.2020.1829689

143 Lucy Knox, Jacinta Douglas & Christine Bigby, '"I've never been a yes person": decision-making participation and self-conceptualization after severe traumatic brain injury', (2017), vol 39(22), *Disability and Rehabilitation*, pp 2250-60.

144 Lucy Knox, Jacinta Douglas & Christine Bigby, '"I've never been a yes person": decision-making participation and self-conceptualization after severe traumatic brain injury', (2017), vol 39(22), *Disability and Rehabilitation*, pp 2250-60.

145 Lucy Knox, Jacinta Douglas & Christine Bigby, '"I've never been a yes person": decision-making participation and self-conceptualization after severe traumatic brain injury', (2017), vol 39(22), *Disability and Rehabilitation*, pp 2250-60; Lucy Knox, Jacinta Douglas & Christine Bigby, '"I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents', (2016), vol 26(2), *Neuropsychological Rehabilitation*, pp 236-60.

146 Lucy Knox, Jacinta Douglas & Christine Bigby, ''The biggest thing is trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI', (2015), vol 29(6), *Brain Injury*, pp 745-57; Christine Bigby & Jacinta Douglas, 'Supported decision making' in Roger J Stancliffe, Michael L Wehmeyer, Karrie A Shogren & Brian H Abery (ed) *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan*, Springer International Publishing, 2020, pp 45-66.

147 Lucy Knox, Jacinta Douglas & Christine Bigby, '"I won't be around forever": understanding the decision-making experiences of adults with severe TBI and their parents', (2016), vol 26(2*), Neuropsychological Rehabilitation*, pp 236-60.

148 See Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, 'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social &Cultural Geography*, DOI: 10.1080/14649365.2020.1829689; and in the context of being critical of perceived inaccurate capacity assessments: Sophie Moore, Rebecca Wotus, Alyson Norman, Mark Holloway & Jackie Dean, 'Behind the cloak of competence: brain injury and mental capacity legislation', (2019), vol 21(4), *The Journal of Adult Protection*, pp 201-18.

149 Lucy Knox, Jacinta Douglas & Christine Bigby, '"I've never been a yes person": decision-making participation and self-conceptualization after severe traumatic brain injury', (2017), vol 39(22), *Disability and Rehabilitation*, pp 2250-60; Lucy Knox, Jacinta Douglas & Christine Bigby, '"I won't be around forever": Understanding the decision-making experiences of adults with severe TBI and their parents', (2016), vol 26(2), *Neuropsychological Rehabilitation*, pp 236-60.

150 Lucy Knox, Jacinta Douglas & Christine Bigby, 'Whose decision is it anyway? How clinicians support decision-making participation after acquired brain injury', (2013), vol 35(22), *Disability and Rehabilitation*, pp 1926-32; Lucy Knox, Jacinta Douglas & Christine Bigby, ''The biggest thing is

trying to live for two people': Spousal experiences of supporting decision-making participation for partners with TBI', (2015), vol 29(6), *Brain Injury*, pp 745-57.

151 Sophie Moore, Rebecca Wotus, Alyson Norman, Mark Holloway & Jackie Dean, 'Behind the cloak of competence: brain injury and mental capacity legislation', (2019), vol 21(4), *The Journal of Adult Protection*, pp 201-18; Alyson Norman, Sophie Moore, Rebecca Wotus, Mark Holloway & Jackie Dean, *Supported Decision Making: Brain injury case managers' experience of mental capacity and the Mental Capacity Act*, (Technical Report, 2018) DOI: 10.13140/RG.2.2.35575.73128

152 Jacinta Douglas, Christine Bigby & Elizabeth Smith, *Building capability to support client decision making: TAC Project No. T005*, Living with Disability Research Centre, La Trobe University, 2020.

153 Kay Wilson, *Mental health law: abolish or reform?*, Oxford University Press, 2021, p 153.

154 Piers Gooding, *A new era for mental health law and policy: supportive decision-making and the UN Convention on the Rights of Persons with Disabilities*, Cambridge University Press, 2017, pp 205-9; see also Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melbourne, 2017, pp 56-7.

155 Gavin Davidson, Lisa Brophy, Jim Campbell, Susan J Farrell, Piers Gooding & Ann-Marie O'Brien, 'An international comparison of legal frameworks for supported and substitute decision-making in mental health services', (2016), vol 44, *International Journal of Law and Psychiatry*, pp 30-40, 31, citing Michelle Browning, Christine Bigby & Jacinta Douglas, 'Supported decision making: understanding how its conceptual link to legal capacity is influencing the development of practice', (2014), vol 1(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 34-45.

156 See eg Jill Stavert, 'The exercise of legal capacity, supported decision-making and Scotland's mental health and incapacity legislation: working with CRPD challenges', (2015), vol 4(2), *Laws*, pp 296-313; Jill Stavert, 'Supported decision-making and paradigm shifts: word play or real change?', (2020), vol 11, *Frontiers in Psychiatry*, pp 571005-571005; Bernadette McSherry, 'Mental health laws: where to from here', (2014), vol 40, *Monash University Law Review*, pp 175-97; Erin Wilson, Robert Campain, Sarah Pollock, Lisa Brophy & Anthony Stratford, 'Exploring the pesonal, programmatic and market barriers to choice in the NDIS for people with psychosocial disability', (2021), *Australian Journal of Sociological Issues,* pp 1-21.

157 Piers Gooding, 'Mind the gap: Researching 'alternatives to coercion' in mental health care' in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 273-87; Wayne Martin & Sándor Gurbai, 'Surveying the Geneva impasse: Coercive care and human rights', (2019), vol 64, *International Journal of Law and Psychiatry*, pp 117-28.

158 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014) [7].

159 Silvana Galderisi, 'The UN Convention on the Rights of Persons with Disabilities: Great opportunities and dangerous interpretations', (2019), vol 18(1), *World Psychiatry*, pp 47-8; Melvyn Colin Freeman, Kavitha Kolappa, Jose Miguel Caldas de Almeida, Arthur Kleinman, Nino Makhashvili, Sifiso Phakathi, Benedetto Saraceno & Graham Thornicroft, 'Reversing hard won victories in the name of human rights: a critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities', (2015), vol 2(9), *The Lancet Psychiatry*, pp 844-9; John Dawson, 'A realistic approach to assessing mental health laws' compliance with the UNCRPD', (2015), vol 40, *International Journal of Law and Psychiatry*, pp 70-9; Mathe Scholten & J Gather, 'Adverse consequences of article 12 of the UN Convention on the Rights of Persons with Disabilities for persons with mental disabilities and an alternative way forward', (2018), vol 44(4), *Journal of Medical Ethics*, pp 226-33; George Szmukler, ''Capacity', 'best interests', 'will and preferences' and the UN Convention on the Rights of Persons with Disabilities', (2019), vol 18(1), *World Psychiatry*, pp 34-41; Katrine Del Villar, 'Should supported decision-making replace substituted decision-making? The Convention on the Rights of Persons with Disabilities and coercive treatment under Queensland's *Mental Health Act 2000'*, (2015), vol 4(2), *Laws*, pp 173-200; José Miguel Caldas de Almeida, 'The CRPD Article 12, the limits of reductionist approaches to complex issues and the necessary search for compromise', (2019), vol 18(1), *World Psychiatry*, pp 46-7.

160 Paul Skowron, ‘Giving substance to ‘the best interpretation of will and preferences’’, (2019), vol 62, *International Journal of Law and Psychiatry*, pp 125-34; George Szmukler, ‘’Capacity’, ‘best interests’, ‘will and preferences’ and the UN Convention on the Rights of Persons with Disabilities’, (2019), vol 18(1), *World Psychiatry*, pp 34-41; Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel, Jacinta Douglas & Elizabeth Smith, ‘Realising ‘Will, Preferences and Rights’: reconciling differences on best practice support for decision-making?’ (2019), vol 28(4), *Griffith Law Review*, pp 357-79.

161 Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel, Jacinta Douglas & Elizabeth Smith, ‘Realising ‘Will, Preferences and Rights’: reconciling differences on best practice support for decision-making?’ (2019), vol 28(4), *Griffith Law Review*, pp 357-79.

162 Sheila M Wildeman, ‘Consent to psychiatric treatment: From insight (into illness) to incite (a riot)’ in Colleen Flood & Jennifer Chandler (ed) *Law and mind: mental health law and policy in Canada*, LexisNexis, 2016.

163 Fauzia Knight, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, KAte Johnston-Ataata & Helen Herrman, ‘Supported decision-making: the expectations held by people with experience of mental illness’, (2018), vol 28(6), *Qualitative Health Research*, pp 1002-15.

164 Fauzia Knight, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, KAte Johnston-Ataata & Helen Herrman, ‘Supported decision-making: the expectations held by people with experience of mental illness’, (2018), vol 28(6), *Qualitative Health Research*, pp 1002-15, 1011.

165 Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melbourne, 2017, pp 37-8.

166 Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melborune, 2017.

167 Fauzia Knight, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, Kate Johnston-Ataata & Helen Herrman, ‘Supported decision-making: the expectations held by people with experience of mental illness’, (2018), vol 28(6), *Qualitative Health Research*, pp 1002-15.

168 Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, ‘Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners’, (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826-33.

169 Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, ‘Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners’, (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826-33; Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melbourne, 2017.

170 Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, ‘Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners’, (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826-33.

171 Lisa Brophy, Renata Kokanovic, Jacinthe Flore, Bernadette McSherry & Helen Herrman, ‘Community treatment orders and supported decision-making’, (2019), vol 10, *Frontiers in Psychiatry*, 414:1-12; Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melbourne, 2017, pp 40-41.

172 Meredith Stone, Renata Kokanovic, Felicity Callard & Alex F Broom, ‘Estranged relations: coercion and care in narratives of supported decision-making in mental healthcare’, (2020), vol 46(1), *Medical Humanities*, pp 62-72.

173 Fauzia Knight, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, KAte Johnston-Ataata & Helen Herrman, ‘Supported decision-making: the expectations held by people with experience of mental illness’, (2018), vol 28(6), *Qualitative Health Research*, pp 1002-15; Shirli Werner & Rachel Chabany, ‘Guardianship law versus supported decision-making policies: perceptions of persons with intellectual or psychiatric disabilities and parents’, (2016), vol 86(5), *American Journal of Orthopsychiatry*, pp 486-99.

174 Shirli Werner & Rachel Chabany, ‘Guardianship law versus supported decision-making policies: perceptions of persons with intellectual or psychiatric disabilities and parents’, (2016), vol 86(5), *American Journal of Orthopsychiatry*, pp 486-99.

175 Giles Newton-Howes & Sarah Gordon, ‘Who controls your future: The convention on the rights of persons with disabilities from a service user focused perspective’, (2020), vol 54(2), *Australian and New Zealand Journal of Psychiatry*, pp 134-7; James Cooney, Michael Daly, Giles Newton-Howes, Kris Gledhill & Sarah Gordon, ‘Making the Convention on the Rights of Persons with Disabilities real: our word is our bond’, (2021), vol 134(1534), *The New Zealand Medical Journal (Online)*, pp 8-10; Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, ‘Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners’, (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826-33.

176 Dilip V Jeste, Graham M L Eglit, Barton W Palmer, Jonathan G Martinis, Peter Blanck & Elyn R Saks, ‘Supported decision making in serious mental illness’, (2018), vol 81(1), *Psychiatry*, pp 28-40.

177 Sarah Hamilton, Paulina Szymczynska, Naomi Clewett, Jill Manthorpe, Jerry Tew, John Larsen & Vanessa Pinfold, ‘The role of family carers in the use of personal budgets by people with mental health problems’, (2017), vol 25(1), *Health & Social Care in the Community*, pp 158-66.

178 Rachel Hale, Bernadette McSherry, Jeannie Marie Paterson, Lisa Brophy & Anna Arstein-Kerslake, *Consumer transactions: Equitable support models for individuals with decision-making impairments: A pilot study supported by the Melbourne Social Equity Institute and the Melbourne Law School Major Collaborative Fund Project*, University of Melbourne, 2017; see also: Yvette Maker, Anna Arstein-Kerslake, Bernadette McSherry, Jannie Marie Paterson & Lisa Brophy, ‘Ensuring equality for persons with cognitive disabilities in consumer contracting: An international human rights law perspective’, (2018),vol 19(1), *Melbourne Journal of International Law,* pp 178-99.

179 Jill Stavert, ‘Paradigm shift or paradigm paralysis? National mental health and capacity law and implementing the CRPD in Scotland’, (2018), vol 7(3), *Laws*, pp 26-41.

180 Kanna Sugiura, Faraaz Mahomed, Shekhar Saxena & Vikram Patel, ‘An end to coercion: rights and decision-making in mental health care’, (2020), vol 98(1), *Bulletin of the World Health Organization*, pp 52-8; Faraaz Mahomed, Michael Ashley Stein, Vikram Patel & Charlene Sunkel, ‘Introduction - A “Paradigm shift” in mental health care’ in Faraaz Mahomed, Michale Ashley Stein, Vikram Patel & Charlene Sunkel (ed) *Mental Health, legal capacity and human rights*, Cambridge University Press, 2021, pp 1-16.

181 Mary Donnelly, ‘Deciding in dementia: the possibilities and limits of supported decision-making’, (2019), vol 66, *International Journal of Law and Psychiatry*, 101466: 1-7.

182 Bhargavi V Davar, ‘Seher’s “Circle of Care” model in advancing supported decision making in India’ in Michael Ashley Stein, Faraaz Mahomed, Vikram Patel & Charlene Sunkel (ed) *Mental Health, Legal Capacity, and Human Rights*, 2021, pp 213-29.

183 Joel D Corcoran, Cindy Hamersma & Steven Manning, ‘The Clubhouse Model: A framework for naturally occurring supported decision making’ in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 260-72.

184 Fiona Morrissey, ‘The United Nations Convention on the Rights of Persons with Disabilities: a new approach to decision-making in mental health law’, (2012), vol 19(5), *European Journal of Health Law*, pp 423-40; Piers Gooding, ‘Supported decision-making: a rights-based disability concept and its implications for mental health law’, (2013), vol 20(3), *Psychiatry, Psychology and Law*, pp 431-51.

185 Fiona Morrissey, ‘The United Nations Convention on the Rights of Persons with Disabilities: a new approach to decision-making in mental health law’, (2012), vol 19(5), *European Journal of Health Law*, pp 423-40.

186 M Cleary, T Raeburn, P Escott, S West & V Lopez, '"Walking the tightrope": the role of peer support workers in facilitating consumers' participation in decision-making', (2018), vol 27(4), *International Journal of Mental Health Nursing*, pp 1266-72.

187 Martin Zinkler, 'Supported decision making in the prevention of compulsory interventions in mental health care', (2019), vol 10(137), *Frontiers in Psychiatry*, p 3, doi: 10.3389/fpsyt.2019.00137

188 Louise Penzenstadler, Andrew Molodynski & Yasser Khazaal, 'Supported decision making for people with mental health disorders in clinical practice: a systematic review', (2020), vol 24(1), *International Journal of Psychiatry in Clinical Practice*, pp 3-9.

189 Piers Gooding, 'Supported decision-making: a rights-based disability concept and its implications for mental health law', (2013), vol 20(3), *Psychiatry, Psychology and Law*, pp 431-51, 444.

190 Terry Carney & Shih-Ning Then, 'Support for decision-making as people age with a cognitive impairment' in Michelle Putnam & Christine Bigby (ed) *Handbook on Ageing with Disability*, Routledge, 2021, pp 186-95.

191 Australian Institute of Health and Welfare, *Dementia in Australia: Web Report (Last updated 20 Sep 2021)* 2021; Quality and Safety Royal Commission into Aged Care, *Dementia in Australia: Nature, Prevalence and Care: Background Paper 3*, 2019.

192 G E Caughey, C E Lang, S C Bray, M Moldovan, R N Jorissen, S Wesselingh & M C Inacio, *International and National Quality and Safety Indicators for Aged Care: Report for the Royal Commission into Aged Care Quality and Safety*, 2020.

193 Rebekah Diller, 'Legal capacity for all: including older persons in the shift from adult guardianship to supported decision-making', (2016), vol 43, *Fordham Urban Law Journal*, pp 495-538; Terry Carney & Shih-Ning Then, 'Support for decision-making as people age with a cognitive impairment' in Michelle Putnam & Christine Bigby (ed) *Handbook on Ageing with Disability*, Routledge, 2021, pp 186-95.

194 Mary Donnelly, 'Deciding in dementia: the possibilities and limits of supported decision-making', (2019), vol 66, *International Journal of Law and Psychiatry*, 101466: pp 1-7; Laura Pritchard-Jones, 'Exploring the potential and the pitfalls of the United Nations Convention on the Rights of Persons with Disabilities and General Comment No. 1 for people with dementia', (2019), vol 66, *International Journal of Law and Psychiatry*, 101467: 1-7; Amanda Keeling, 'Supported decision making: the rights of pople with dementia'', (2016), vol 30(30), *Nursing Standard*, pp 38-44.

195 See, for example, Terry Carney & Shih-Ning Then, 'Support for decision-making as people age with a cognitive impairment' in Michelle Putnam & Christine Bigby (ed) *Handbook on Ageing with Disability*, Routledge, 2021, pp 186-95; Andrew Peterson, Jason Karlawish & Emily Largent, 'Supported decision making with people at the margins of autonomy', (2020), *The American Journal of Bioethics*, pp 1-21; cf Leslie P Francis, 'Supported decisions as the patient's own?', (2021), 11 *The American Journal of Bioethics*, pp 24-26

196 Megan Wright, 'Dementia, cognitive transformation, and supported decision making', (2020), vol 20(8), *American journal of bioethics*, pp 88-90, 88; Terry Carney, 'Combating elder abuse: any role for supported-decision-making, adult guardianship or other laws?' in Mala Kapur Shankardass (ed) *Combating Elder Abuse in Australia and India*, Nova Science, 2020, pp 265-87; Anita Smith & Danny Sullivan, 'A new ball game: the United Nations Convention on the Rights of Persons with Disabilities and assumptions in care for people with dementia', (2012), vol 20(1), *Journal of Law and Medicine*, pp 28-34.

197 Mary Donnelly, 'Deciding in dementia: the possibilities and limits of supported decision-making', (2019), vol 66, *International Journal of Law and Psychiatry*, 101466: pp 1-7, 3; see also Deirdre Fetherstonhaugh, Laura Tarzia, Michael Bauer, Rhonda Nay & Elizabeth Beattie, '"The red dress or the blue?": how do staff perceive that they support decision making for people with dementia living in residential aged care facilities?', (2016), vol 35(2), *Journal of Applied Gerontology*, pp 209-26.

198 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": Views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 598-608, 601; see also Agnieszka Jaworska & Winston Chiong, 'Supported decision-making for people with dementia should focus on their values', (2021), vol 21(11), *The American Journal of Bioethics*, pp 19-21.

199 Megan Wright, ‘Dementia, cognitive transformation, and supported decision making’, (2020), vol 20(8), *American Journal of Bioethics*, pp 88-90.

200 Megan Wright, ‘Dementia, cognitive transformation, and supported decision making’, (2020), vol 20(8), *American Journal of Bioethics*, pp 88-90.

201 Meredith Blake, Cameron Stewart, Pia Castelli-Arnold & Craig Sinclair, ‘Supported decision-making for people living with dementia: an examination of four Australian guardianship laws’, (2021), vol 28(2), *Journal of Law and Medicine*, pp 389-420.

202 Craig Sinclair, Kate Gersbach, Michelle Hogan, Romola S Bucks, Kirsten A Auret, Josephine M Clayton, Meera Agar & Sue Kurrle, ‘How couples with dementia experience healthcare, lifestyle, and everyday decision-making’, (2018), vol 30(11), *International Psychogeriatrics*, pp 1639-47; see also the experiences described in Kritika Samsi & Jill Manthorpe, ‘Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers’, (2013), vol 25(6), *International Psychogeriatrics*, pp 949-61.

203 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A real bucket of worms”: views of people living with dementia and family members on supported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587-608, 601.

204 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A real bucket of worms”: views of people living with dementia and family members on supported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587-608, 601.

205 Deirdre Fetherstonhaugh, Laura Tarzia & Rhonda Nay, ‘Being central to decision making means I am still here!: The essence of decision making for people with dementia’, (2012), vol 27(2), *Journal of Aging Studies*, pp 143-50.

206 Deirdre Fetherstonhaugh, Laura Tarzia & Rhonda Nay, ‘Being central to decision making means I am still here!: the essence of decision making for people with dementia’, (2012), vol 27(2), *Journal of Aging Studies*, pp 143-50.

207 Craig Sinclair, Kate Gersbach, Michelle Hogan, Romola S Bucks, Kirsten A Auret, Josephine M Clayton, Meera Agar & Sue Kurrle, ‘How couples with dementia experience healthcare, lifestyle, and everyday decision-making’, (2018), vol 30(11), *International Psychogeriatrics*, pp 1639-47.

208 Sarah E Keyes, Charlotte L Clarke & Catherine E Gibb, ‘Living with dementia, interdependence and citizenship: Narratives of everyday decision-making’, (2019), vol 34(2), *Disability & Society*, pp 296-319, 106-7.

209 Sarah E Keyes, Charlotte L Clarke & Catherine E Gibb, ‘Living with dementia, interdependence and citizenship: Narratives of everyday decision-making’, (2019), vol 34(2), *Disability & Society*, pp 296-319, 106-7.

210 Amanda Keeling, ‘Supported decision making: the rights of pople with dementia’’, (2016), vol 30(30), *Nursing Standard*, pp 38-44; see also Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton & Helen Radoslovich, ‘Professionals’ views and experiences in supporting decision-making involvement for people living with dementia’, (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84-105.

211 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A real bucket of worms”: views of people living with dementia and family members on supported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587-608, 593.

212 Deirdre Fetherstonhaugh, Laura Tarzia & Rhonda Nay, ‘Being central to decision making means I am still here!: the essence of decision making for people with dementia’, (2012), vol 27(2), *Journal of Aging Studies*, pp 143-50; Jeremy Dixon, Sarah Donnelly, Jim Campbell & Judy Laing, ‘Safeguarding people living with dementia: how social workers can use supported decision-making strategies to support the human rights of individuals during adult safeguarding enquiries’, (2021), *The British Journal of Social Work*, pp 1-18; Craig Sinclair, Susan Kurrle, Sue Field,

Meera Agar, Kathy Williams, Romola Bucks, Josephine Clayton, Cameron Stewart, Meredith Blake, Kirsten Auret, Meredith Gresham, Angelilta Martini & Helen Radoslovich, *Supported Decision-Making in Dementia Care: Final Project Report*, NHMRC Cognitive Decline Partnership Centre, 2019, p 14; Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton & Helen Radoslovich, 'Professionals' views and experiences in supporting decision-making involvement for people living with dementia', (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84-105.

213 Deirdre Fetherstonhaugh, Laura Tarzia, Michael Bauer, Rhonda Nay & Elizabeth Beattie, '"The red dress or the blue?": how do staff perceive that they support decision making for people with dementia living in residential aged care facilities?', (2016), vol 35(2), *Journal of Applied Gerontology*, pp 209-26; Craig Sinclair, Susan Kurrle, Sue Field, Meera Agar, Kathy Williams, Romola Bucks, Josephine Clayton, Cameron Stewart, Meredith Blake, Kirsten Auret, Meredith Gresham, Angelilta Martini & Helen Radoslovich, *Supported Decision-Making in Dementia Care: Final Project Report*, NHMRC Cognitive Decline Partnership Centre, 2019, p 14.

214 Deirdre Fetherstonhaugh, Laura Tarzia, Michael Bauer, Rhonda Nay & Elizabeth Beattie, '"The red dress or the blue?": How do staff perceive that they support decision making for people with dementia living in residential aged care facilities?', (2016), vol 35(2), *Journal of Applied Gerontology*, pp 209-26.

215 Craig Sinclair, Susan Kurrle, Sue Field, Meera Agar, Kathy Williams, Romola Bucks, Josephine Clayton, Cameron Stewart, Meredith Blake, Kirsten Auret, Meredith Gresham, Angelilta Martini & Helen Radoslovich, *Supported Decision-Making in Dementia Care: Final Project Report*, NHMRC Cognitive Decline Partnership Centre, 2019; Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton & Helen Radoslovich, 'Professionals' views and experiences in supporting decision-making involvement for people living with dementia', (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84-105; see also Theresa S Wied, Maren Knebel, Valentina A Tesky & Julia Haberstroh, 'The human right to make one's own choices – implications for supported decision-making in persons with dementia: A systematic review', (2019), vol 24(2), *European Psychologist*, pp 152-153.

216 Kevin De Sabbata & Elena Syurina, *Supported decision-making and dementia*, Psychiatrie Verlag, 2019, p 25.

217 Lyndsey M Miller, Christopher S Lee, Carol J Whitlatch & Karen S Lyons, 'Involvement of hospitalized persons with dementia in everyday decisions: a dyadic study', (2018), vol 58(4), *The Gerontologist*, pp 644-53.

218 Geraldine Boyle, ''She's usually quicker than the calculator': financial management and decision-making in couples living with dementia', (2013), vol 21(5), *Health & Social Care in the Community*, pp 554-62.

219 Cheryl Tilse, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, 'Managing older people's money: assisted and substitute decision making in residential aged-care', (2011), vol 31(1), *Ageing & Society*, pp 93-109.

220 Cheryl Tilse, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, 'Managing older people's money: assisted and substitute decision making in residential aged-care', (2011), vol 31(1), *Ageing & Society*, pp 93-109.

221 Cheryl Tilse, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, 'Managing older people's money: assisted and substitute decision making in residential aged-care', (2011), vol 31(1), *Ageing & Society*, pp 93-109.

222 Cheryl Tilse, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, 'Managing older people's money: assisted and substitute decision making in residential aged-care', (2011), vol 31(1), *Ageing & Society*, pp 93-109, 106.

223 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587-608, 595.

224 Alessandro Bosco, Justine Schneider, Donna Maria Coleston-Shields, Kaanthan Jawahar, Paul

Higgs & Martin Orrell, ‘Agency in dementia care: systematic review and meta-ethnography’, (2019), vol 31(5), *International Psychogeriatrics*, pp 627-62.

225 Karen Strickland, Kasia Bail, Sarah Cope, Murray Turner & Cameron Moss, ‘Supported decision-making to assist older persons experiencing elder abuse: An integrative review’, (2021), vol 28(4), *Collegian*, pp 447-55.

226 See Laura Pritchard-Jones, ‘Exploring the potential and the pitfalls of the United Nations Convention on the Rights of Persons with Disabilities and General Comment No. 1 for people with dementia’, (2019), vol 66, *International Journal of Law and Psychiatry*, 101467: pp 1-7.

227 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A real bucket of worms”: views of people living with dementia and family members on supported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587-608.

228 Canadian Centre for Elder Law, *Study Paper on Inclusive Investing: Respecting the Rights of Vulnerable Investors through Supported Decision-Making*, 2021.

229 Terry Carney, ‘Combating elder abuse: Any role for supported-decision-making, adult guardianship or other laws?’ in Mala Kapur Shankardass (ed) *Combating Elder Abuse in Australia and India*, Nova Science, 2020, pp 265-87.

230 Jamie Bryant, Marcus Sellars, Craig Sinclair, Karen Detering, Kimberly Buck, Amy Waller, Ben White & Linda Nolte, ‘Inadequate completion of advance care directives by individuals with dementia: national audit of health and aged care facilities’ (2021) *BMJ Supportive & Palliative Care*, 0: pp 1–10.

231 Terry Carney & Shih-Ning Then, ‘Support for decision-making as people age with a cognitive impairment’ in Michelle Putnam & Christine Bigby (ed) *Handbook on Ageing with Disability*, Routledge, 2021, pp 186-95.

232 Haberstroh, J & Oswald J Pantel, ‘Ensure Project: supported decision-making and capacity assessment in clinical dementia research’, (2017), vol 1(S1), *Innovation in Aging*; see also Julia Haberstroh, Susanne Penger, Anne Messemaker & Maren Knebel, ‘Observational assessment of communication to empower patients with dementia to make legally effective decisions - revalidation of CODEM(amb)’, (2021), *Aging & Mental Health*, DOI: 10.1080/13607863.2021.1952549

233 Theresa S Wied, Aoife Poth, Johannes Pantel, Frank Oswald & Julia Haberstroh, ‘How do dementia researchers view support tools for informed consent procedures of persons with dementia?’, (2020), *Zeitschrift Fur Gerontologie Und Geriatrie*, https://doi.org/10.1007/s00391-020-01779-2; Theresa Wied, Matthe Scholten, Julia Haberstroh & Johanne Pantel, ‘Supported Decision-Making in persons with dementia: development of an enhanced consent procedure for lumbar puncture,https://www.researchgate.net/profile/Matthe-Scholten/publication/356266883_

234 Ulrika Ferm, Steven J Bloch & Charlotta Saldert, ‘Negotiating disagreement in picture symbol supported decision making’, (2016), vol 6(2), *Journal of Interactional Research in Communication Disorders*, pp 131-56, 133.

235 Joan Murphy & Tracey Oliver, ‘The use of Talking Mats to support people with dementia and their carers to make decisions together’, (2013), vol 21(2), *Health & Social Care in the Community*, pp 171-80, 177.

236 Ulrika Ferm, Steven J Bloch & Charlotta Saldert, ‘Negotiating disagreement in picture symbol supported decision making’, (2016), vol 6(2), *Journal of Interactional Research in Communication Disorders*, pp 131-56, 144.

237 Julia Lühnen, Burkhard Haastert, Ingrid Mühlhauser & Tanja Richter, ‘Informed decision-making with and for people with dementia - efficacy of the PRODECIDE education program for legal representatives: protocol of a randomized controlled trial (PRODECIDE-RCT)’, (2017), vol 17(1), *BMC Geriatrics*, 217: 1-11.

238 Julia Lühnen, Burkhard Haastert, Ingrid Mühlhauser & Tanja Richter, ‘Informed decision-making with and for people with dementia - efficacy of the PRODECIDE education program for legal representatives: protocol of a randomized controlled trial (PRODECIDE-RCT)’, (2017), vol 17(1), *BMC Geriatrics*, 217: pp 1-11.

239 Jayne Clapton, Lesley Chenoweth, Natalie Clements, Vicki Pascoe, Kylie Radal, Yvonne Cadet James, Val Wallace & Diane Cadet-James, *Impaired Decision-Making Capacity and Indigenous*

Queenslanders: Final Report for the Office of the Public Advocate, Queensland, State of Qld, Department of Justice and Attorney-General, 2011, pp 9.

240 Shouli Shahid, Emma V Taylor, Shelley Cheetham, John A Woods, Samar M Aoun & Sandra C Thompson, 'Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: a comprehensive review', (2018,) vol 17(1) *BMC Palliative Care*, 72: pp 1-20.

241 Christiane Purcal, Trish Hill, Kelley Johnson & Rosemary Kayess, 'Evaluation of the Supported Decision Making Phase 2 (SDM2) project: final report' (Prepared for NSW Trustee and Guardian with the NSW Public Guardian, May 2017); Office of the Public Advocate (Qld), *Decision-making Support and Queensland's Guardianship System: a systemic advocacy report*, 2016, p 180.

242 Karen Soldatic, Georgia van Toorn, Leanneand Dowse & Kirsty Muir, 'Intellectual disability and complex intersections: marginalisation under the National Disability Insurance Scheme', (2014), vol 1(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 6-16, 11; see also: Eileen Baldry, Ruth McCausland, Leanne Dowse & Elizabeth McEntyre, *A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system*, University of New South Wales, 2015.

243 Eileen Baldry, Ruth McCausland, Leanne Dowse & Elizabeth McEntyre, *A predictable and preventable path: aboriginal people with mental and cognitive disabilities in the criminal justice system*, University of New South Wales, 2015, p 13.

244 Office of the Public Advocate (Vic), *Walk with me, talk with me: a practice guide for OPA staff*, 2018.

245 Cheryl Tilse, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, 'Managing older people's money: assisted and substitute decision making in residential aged-care', (2011), vol 31(1), *Ageing & Society*, pp 93-109.

246 Lana Zannettino, Dale Bagshaw, Sarah Wendt & Valerie Adams, 'The role of emotional vulnerability and abuse in the financial exploitation of older people from culturally and linguistically diverse communities in Australia', (2015), vol 27(1), *Journal of Elder Abuse & Neglect*, pp 74-89.

247 Lana Zannettino, Dale Bagshaw, Sarah Wendt & Valerie Adams, 'The role of emotional vulnerability and abuse in the financial exploitation of older people from culturally and linguistically diverse communities in Australia', (2015), vol 27(1), *Journal of Elder Abuse & Neglect*, pp 74-89, 74.

248 Canadian Centre for Elder Law, *Study Paper on Inclusive Investing: Respecting the Rights of Vulnerable Investors through Supported Decision-Making*, 2021, pp 198.

249 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": Views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587-608, 591.

250 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587-608, 598.

251 Craig Sinclair, Susan Kurrle, Sue Field, Meera Agar, Kathy Williams, Romola Bucks, Josephine Clayton, Cameron Stewart, Meredith Blake, Kirsten Auret, Meredith Gresham, Angelilta Martini & Helen Radoslovich, *Supported Decision-Making in Dementia Care: Final Project Report*, NHMRC Cognitive Decline Partnership Centre, 2019, pp 28.

252 Sandra B Vanegas, Sandy Magaña, Weiwen Zeng & Carlos Pavon 'Decision making and culturally diverse individuals with IDD and their families: A call for research' in Ishita Khemka & Linda Hickson (ed) *Decision Making by Individuals with Intellectual and Developmental Disabilities: Integrating Research into Practice*, Springer International Publishing, 2021, pp 221-51.

253 Nancy J Knauer, 'LGBT Issues and adult guardianship: a comparative perspective' in Kim Dayton (ed) *Comparative perspectives in guardianship*, University of Carolina Press, 2013.

254 Nathan J Wilson, Jemima Macdonald, Brenda Hayman, Alexandra M Bright, Patsie Frawey & Gisselle Gallego, 'A narrative review of the literature about people with intellectual disability who identify as lesbian, gay, bisexual, transender, intersex or questioning', (2018), vol 22(2), *Journal of Intellectual Disabilities*, pp 79-96; Elizabeth Smith, Tessa-May Zirnsak, Jennifer Power, Anthony

Lyons & Christine Bigby, 'Social inclusion of LGBTQ and gender diverse adults with intellectual disability in disability services: a systematic review of the literature', (2021), *Journal of applied research in intellectual disabilities*, DOI: 10.1111/jar.12925.

255 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014).

256 Geraldine Boyle, ''She's usually quicker than the calculator': financial management and decision-making in couples living with dementia', (2013), vol 21(5), *Health & Social Care in the Community*, pp 554-62.

257 Lois Bedson, John Chesterman & Michael Woods, 'The prevalence of elder abuse among adult guardianship clients', (2018), vol 18, *Macquarie Law Jorunal*, pp 15-53.

258 'The Convention on the Rights of Persons with Disabilities recognizes that women with disabilities may be subject to multiple and intersectional forms of discrimination based on gender and disability. For example, women with disabilities are subjected to high rates of forced sterilization, and are often denied control of their reproductive health and decision-making, the assumption being that they are not capable of consenting to sex': Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014); see also Carolyn Frohmader & Therese Sands, *Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings'*, Australian Cross Disability Alliance (ACDA), 2015.

259 Camillia Kong, 'The Convention for the Rights of Persons with Disabilities and article 12: prospective feminist lessons against the "will and preferences" paradigm', (2015), vol 4(4), *Laws*, pp 709-28.

260 See eg R Jamieson, K Theodore & R Raczka, 'Becoming a mother: supported decision-making in context', (2016), vol 20(4), *Journal of Intellectual Disabilities*, pp 313-28; Iffat Naeem & Tanvir Chowdhury Turin, 'Ethical dilemmas and legal ambivalence affects the midwives' perception for providing sexual and reproductive health consultation to women with intellectual disability', (2021), vol 24(2), *Evidence-Based Nursing*, 49-49; Jorge V Verlenden, Jeanne Bertolli & Lee Warner, 'Contraceptive practices and reproductive health considerations for adolescent and adult women with intellectual and developmental disabilities: A review of the literature', (2019), vol 37, *Sexuality and Disability*, pp 541-57; Jeanne Snelling, 'Sexual health, reproductive liberty and adults with impaired capacity' in Iris Reuvecamp & John Dawson (ed) *Mental capacity law in New Zealand*, Thomson Reuters, 2019, pp 251-65. It should be noted that research in this area is appropriately not limited to women who are legal adults but includes younger women of reproductive age (the scope of this review is limited to research relating to adults).

261 Rosie Harding & Ezgi Taşcioğlu, ''That's a bit of a minefield': supported decision making in intellectually disabled people's intimate lives' in C Ashford & A Maine (ed) *Research handbook on gender, sexuality and law*, Edward Elgar, 2020, pp 256-70; see also Jasmine E Harris, 'The role of support in sexual decision-making for people with intellectual and developmental disabilities', (2016), vol 77, *Ohio State Law Journal Furthermore*, pp 83-104, 84-85.

262 R Jamieson, K Theodore & R Raczka, 'Becoming a mother: supported decision-making in context', (2016), vol 20(4), *Journal of Intellectual Disabilities*, pp 313-28.

263 Michelle McCarthy, Claire Bates, Nicola Elson, Siobhan Hunt, Karen Milne-Skillman & Rachel Forrester–Jones, ''Love makes me feel good inside and my heart is fixed': what adults with intellectual disabilities have to say about love and relationships', (2021), *Journal of Applied Research in Intellectual Disabilities*, 00:1–11.

264 Rosie Harding, Ezgi Taşcioğlu & Magdalena Furgalska, *Supported will making: a socio-legal study of experiences, values, and potential in supporting testamentary capacity*, Birmingham Law School, University of Birmingham, 2019.

265 Megan S Wright, 'Equality of autonomy? Physician aid in dying and supported decision-making', (2021), vol 63(1), *Arizona Law Review*, pp 157-98.

266 Terry Carney & Fleur Beaupert, 'Public and private bricolage: challenges balancing law, services and civil society in advancing the CRPD supported decision making', (2013), vol 36(1), *University of New South Wales Law Journal*, pp 175-201; John Chesterman, 'Modernising adult protection in an age of choice', (2014), vol 73(4), *Australian Journal of Public Administration*, pp 517-24;

Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel & Jacinta Douglas, ‘National disability insurance scheme plan decision-making: Or when tailormade case planning met taylorism & the algorithms?’, (2019), vol 42(3), *Melbourne University Law Review*, pp 780—812; Elyse Perry, Rebecca Waters & Angus Buchanan, ‘Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability’, (2019), vol 54(3), *The Australian Journal of Social Issues*, pp 210-23; Office of the Public Advocate (Vic), *Decision Time: Activating the rights of adults with cognitive disability*, *Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, 2021, p 25.

267 Christine Bigby, Mary Whiteside & Jacinta Douglas, *Supporting people with cognitive disabilities in decision making – processes and dilemmas*, Living with Disability Research Centre, La Trobe University, 2015, pp 4; Bruce Alston, ‘Towards supported decision-making: article 12 of the Convention on the Rights of Persons with Disabilities and guardianship law reform’, (2017), vol 35(2), *Law in Context*, pp 21-39; Office of the Public Advocate (Vic), *Decision Time: Activating the rights of adults with cognitive disability*, 2021.

268 Emily Cukalevski, ‘Supporting choice and control—an analysis of the approach taken to legal capacity in Australia’s National Disability Insurance Scheme’, (2019), vol 8(2), *Laws*, pp 1-19.

269 Emily Cukalevski, ‘Supporting Choice and control—an analysis of the approach taken to legal capacity in Australia’s National Disability Insurance Scheme’, (2019), vol 8(2), *Laws*, pp 1-19.

270 Christine Bigby, Jacinta Douglas, Terry Carney, Shih-Ning Then, Ilan Wiesel & Elizabeth Smith, ‘Delivering decision making support to people with cognitive disability - what has been learned from pilot programs in Australia from 2010 to 2015’, (2017), vol 52(3), *Australian Journal of Social Issues*, pp 222-40.

271 Emily Cukalevski, ‘Supporting choice and control—an analysis of the approach taken to legal capacity in Australia’s National Disability Insurance Scheme’, (2019), vol 8(2), *Laws*, pp 1-19; see also National Disability Advocacy Program | Department of Social Services, Australian Government (dss.gov.au) retrieved 27 Oct 2021; Australian Government Department of Social Services, *Annual Report 2020-21*, Commonwealth of Australia, 2021, pp 116-117; examples of guidance material produced for supported decision-making in the NDIS include: National Disability Services, ‘People with Disability and Supported Decision-Making in the NDIS: A Guide for NSW Providers’ (20xx) https://www.nds.org.au/resources/people-with-disability-and-supported-decision-making-in-the-ndis-a-guide-for-nsw-providers’; Office of the Public Advocate (Vic), ‘Guide to NDIS decision-making. When a decision can be made by, with, or for an adult with significant cognitive disability’ (2018); Mental Health Australia & ACT Disability Aged and Carer Advocacy Service (ADACAS), ‘Fact sheet. Supported Decision Making, Psychosocial Disability and the National Disability Insurance Scheme*’* (2016) https://mhaustralia.org/sites/default/files/docs/supported_decision_making_fact_sheet.pdf

272 David Tune, *Review of the National Disability Insurance Scheme Act 2013; Removing red tape and implementing the NDIS participant service guarantee* (2019), p 13 NDIS Act Review - final - with accessibility and prepared for publishing1 (dss.gov.au)

273 National Disability Insurance Agency, *National Disability Insurance Scheme Consultation Paper: Supporting you to make your own decisions*, 2021.

274 National Disability Insurance Agency, *Companion Paper: Supporting you to make your own decisions*, *Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, 2021.

275 Emily Cukalevski, ‘Supporting choice and control—An analysis of the approach taken to legal capacity in Australia’s National Disability Insurance Scheme’, (2019), vol 8(2), *Laws*, pp 1-19.

276 John Chesterman, ‘Modernising adult protection in an age of choice’, (2014), vol 73(4), *Australian journal of Public Administration*, 517-24; Emily Cukalevski, ‘Supporting choice and control—An analysis of the approach taken to legal capacity in Australia’s National Disability Insurance Scheme’, (2019), vol 8(2), *Laws*, 1-19; Office of the Public Advocate (Vic), *Decision Time: Activating the rights of adults with cognitive disability*, *Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, (2021),p 29.

277 Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel & Jacinta Douglas, ‘National disability insurance scheme plan decision-making: or when tailormade case planning met taylorism & the algorithms?’, (2019), vol 42(3), *Melbourne University law review*, 780-812.

278 Office of the Public Advocate (Vic), *Decision Time: Activating the rights of adults with cognitive disability*, *Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, (2021), pp vi, 29-30.

279 Elyse Perry, Rebecca Waters & Angus Buchanan, 'Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability', (2019), vol 54(3), *The Australian Journal of Social Issues*, pp 210-23.

280 Elyse Perry, Rebecca Waters & Angus Buchanan, 'Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability', (2019), vol 54(3), *The Australian Journal of Social Issues*, pp 210-23.

281 Elyse Perry, Rebecca Waters & Angus Buchanan, 'Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability', (2019), vol 54(3), *The Australian Journal of Social Issues*, pp 210-23.

282 Jan Lloyd, Karen Moni, Monica Cuskelly & Anne Jobling, 'Exploring the complexity of implementing National Disability Insurance Scheme plans for adults with intellectual disability: Parents' perspectives', (2021), *Journal of Intellectual & Developmental Disability*, pp 281-90.

283 Angela Dew & Leanne Dowse, *The relational nature of planning with people with intellectual disability and complex support needs*, Australasian Society for the Study of Intellectual Disability, 2018, pp 20-4.

284 Susan Collings, Angela Dew & Leanne Dowse, '"They need to be able to have walked in our shoes": what people with intellectual disability say about National Disability Insurance Scheme planning', (2019), vol 44(1), *Journal of Intellectual & Developmental Disability*, pp 1-12; '...families and carers were important in planning and review meetings to provide a broad picture of the NDIS participants' needs and preferences': Carmel Laragy & Karen Raewen Fisher, 'Choice, control and individual funding: The Australian National Disability Insurance Scheme' in Roger A Stancliffe, M L Wehmeyer, K A Shogren & Brian H Abery (ed) *Choice, preference and disability: Promoting self-determination across the lifespan*, Springer, 2020, pp 133-54, 145.

285 Christine Bigby, 'Dedifferentiation and people with intellectual disabilities in the Australian National Disability Insurance Scheme: bringing research, politics and policy together', (2020), vol 45(4), *Journal of Intellectual & Developmental Disability*, pp 309-19.

286 Carmel Laragy & Karen Raewen Fisher, 'Choice, control and individual funding: the Australian National Disability Insurance Scheme' in Roger A Stancliffe, M L Wehmeyer, K A Shogren & Brian H Abery (ed) *Choice, preference and disability: Promoting self-determination across the lifespan*, Springer, 2020, pp 133-54, 142.

287 Kate Higgins & Cassy Nunan, 'Choice and control: why peer education is vital in supporting people with a lived experience of mental illness to exercise choice and control under the NDIS', (2014), vol 27(5), *Parity*, pp 52-3.

288 Claire Spivakovsky, 'Barriers to the NDIS for people with intellectual disability and/or complex support needs involved with the criminal justice systems: the current state of literature ', (2021) vol 46(4), *Journal of Intellectual and Developmental Disability*, pp 329-39.

289 See: India Bohanna, Juliette Catherall & Kylie Dingwall, 'Ensuring Indigenous Australians with acquired brain injuries have equitable access to the National Disability Insurance Scheme', (2013), vol 37(6), *Australian and New Zealand Journal of Public Health*, pp 587-587.

290 Tess Gordon, Angela Dew & Leanne Dowse, 'Listen, learn, build, deliver? Aboriginal and Torres Strait Islander policy in the National Disability Insurance Scheme', (2019), vol 54(3), *Australian Journal of Social Issues*, pp 224-44, 225; see also: 'The historical impacts of colonisation on Indigenous individual, family and community continue to challenge...their trust in governmental systems...' Do Lan Phuong, 'How well does the Australian National Disability Insurance Scheme respond to the issues challenging Indigenous people with disability?', *Aotearoa New Zealand Association of Social Workers*, (2017), pp 49-60, 52.

291 Tess Gordon, Angela Dew & Leanne Dowse, 'Listen, learn, build, deliver? Aboriginal and Torres Strait Islander policy in the National Disability Insurance Scheme', (2019), vol 54(3), *Australian Journal of Social Issues*, pp 224-44.

292 Tess Gordon, Angela Dew & Leanne Dowse, 'Listen, learn, build, deliver? Aboriginal and Torres Strait Islander policy in the National Disability Insurance Scheme', (2019), vol 54(3), *Australian Journal of Social Issues*, pp 224-44, 225-6.

293 Angela Dew & Leanne Dowse, *The relational nature of planning with people with intellectual*

disability and complex support needs, Australasian Society for the Study of Intellectual Disability, 2018, pp 20-4.

294 Do Lan Phuong, ‘How well does the Australian National Disability Insurance Scheme respond to the issues challenging Indigenous people with disability*?*’, (2017), vol 29(4) *Aotearoa New Zealand Association of Social Workers*, pp 49-60, 52, 54.

295 Do Lan Phuong, ‘How well does the Australian National Disability Insurance Scheme respond to the issues challenging Indigenous people with disability*?*’, (2017), vol 29(4) *Aotearoa New Zealand Association of Social Workers*, pp 49-60.

296 Karen Soldatic, Georgia van Toorn, Leanneand Dowse & Kirsty Muir, ‘Intellectual Disability and complex intersections: Marginalisation under the National Disability Insurance Scheme’, (2014), vol 1(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 6-16, 10.

297 54% as reported in: Australian Institute of Health and Welfare, *Dementia in Australia: Web Report* (Last updated 20 Sep 2021, retrieved 11 November 2021) Dementia in Australia, Aged care and support services used by people with dementia - Australian Institute of Health and Welfare (aihw.gov.au) See also: Royal Commission into Aged Care, Quality and Safety, *Dementia in Australia: Nature, Prevalence and Care: Background Paper 3*, 2019.

298 Cheryl Tilse, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, ‘Managing older people’s money: assisted and substitute decision making in residential aged-care’, (2011), vol 31(1), *Ageing & Society*, pp 93-109; Christine Bigby, ‘Known well by no-one: trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community’, (2008), vol 33(2), *Journal of Intellectual & Developmental Disability*, pp 148-57; and in the United Kingdom: Kari Lislerud Smebye, Marit Kirkevold & Knut Engedal, ‘How do persons with dementia participate in decision making related to health and daily care? A multi-case study’, (2012), vol 12(1), *BMC Health Services Research*, pp 241-241.

299 Cheryl Tilse & Jill Wilson, ‘Recognising and responding to financial abuse in residential aged care’, (2013), vol 15(3), *The Journal of Adult Protection*, pp 141-52; Kari Lislerud Smebye, Marit Kirkevold & Knut Engedal, ‘How do persons with dementia participate in decision making related to health and daily care? A multi-case study’, (2012), vol 12(1), *BMC Health Services Research*, pp 241-241.

300 See, for example, Laura Tarzia, Deirdre Fetherstonhaugh & Michael Bauer, ‘Dementia, sexuality and consent in residential aged care facilities’, (2012), vol 38(10), *Journal of Medical Ethics: Journal of the Institute of Medical Ethics*, pp 609-13.; James M Wilkins, ‘More than capacity: alternatives for sexual secision making for individuals with dementia’, (2015), vol 55(5), *The Gerontologist*, pp 716-23.

301 Cheryl Tilse, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, ‘Managing older people’s money: assisted and substitute decision making in residential aged-care’, (2011), vol 31(1), *Ageing & Society*, pp 93-109.

302 Bethany Brown, ‘“For your own good:” Choice and the dangers of institutionalisation for older people’, (2018), vol 27(1), *Human Rights Defender*, pp 12-14; Craig Sinclair, Sue Field, Meredith Blake & Helen Radoslovich, ‘An examination of organisational policies for healthcare and lifestyle decision-making among Australian aged care providers’, (2019), vol 38(S2), *Australasian Journal on Ageing*, pp 90-7.

303 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, 2014.

304 For the National Decision-Making principles see above at Section Implementation challenges.

305 Craig Sinclair, Sue Field, Meredith Blake & Helen Radoslovich, ‘An examination of organisational policies for healthcare and lifestyle decision-making among Australian aged care providers’, (2019), vol 38(S2), *Australasian Journal on Ageing*, pp 90-7.

306 Australian Government Aged Care Quality and Safety Commission, *Guidance and Resources for Providers to support the Aged Care Quality Standards*, Aged Care Quality and Safety Commission, March 2021, referencing, Craig Sinclair, Meredith Blake & Sue Field, *Supported decision-making in aged care: A policy development guideline for aged care providers in Australia*, Cognitive Decline Partnership Centre, 2018.

307 Craig Sinclair, Sue Field, Meredith Blake & Helen Radoslovich, ‘An examination of organisational

policies for healthcare and lifestyle decision-making among Australian aged care providers', (2019), vol 38(S2), *Australasian Journal on Ageing*, pp 90-7.

308 Johannes H Österholm, Annika T Larsson & Anna Olaison, 'Handling the dilemma of self-determination and dementia: a study of case managers' discursive strategies in assessment meetings', (2015), vol 58(6), *Journal of Gerontological Social Work*, pp 613-36; Lottie Giertz, Ulla Melin Emilsson & Emme-Li Vingare, 'Family caregivers and decision-making for older people with dementia', (2019), vol 41(3), *The Journal of Social Welfare & Family Law*, pp 321-38.

309 Annika Taghizadeh Larsson & Johannes H Österholm, 'How are decisions on care services for people with dementia made and experienced? A systematic review and qualitative synthesis of recent empirical findings', (2014), vol 26(11), *International Psychogeriatrics*, pp 1849-62, 1850.

310 Annika Taghizadeh Larsson & Johannes H Österholm, 'How are decisions on care services for people with dementia made and experienced? A systematic review and qualitative synthesis of recent empirical findings', (2014), vol 26(11), *International Psychogeriatrics*, pp 1849-62; J H Osterholm, A T Larsson & A Olaison, 'Handling the dilemma of self-determination and dementia: A study of case managers' discursive strategies in assessment meetings', (2015), vol 58(6), *Journal of Gerontological Social Work*, pp 613-26.

311 Craig Sinclair, Meredith Blake & Sue Field, *Supported decision-making in aged care: A policy development guideline for aged care providers in Australia*, Cognitive Decline Partnership Centre, 2018.

312 Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton & Helen Radoslovich, 'Professionals' views and experiences in supporting decision-making involvement for people living with dementia', (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84-105.

313 Megan S Wright, 'Implementing ethical and legal supported decision making: Some unresolved issues', (2021), vol 21(11), *The American Journal of Bioethics*, pp 40-2.

314 Craig Sinclair, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton & Helen Radoslovich, 'Professionals' views and experiences in supporting decision-making involvement for people living with dementia', (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84-105.

315 Sarah Donnelly, Diarmuid Ó Coimín, Deidre O'Donnell, Éidín Ní Shé, Carmel Davies, Lauren Christophers, Steve Mc Donald & Thilo Kroll, 'Assisted decision-making and interprofessional collaboration in the care of older people: a qualitative study exploring perceptions of barriers and facilitators in the acute hospital setting', (2021), *Journal of interprofessional Care,* pp 1-11.

316 William F Sullivan & John Heng, 'Supporting adults with intellectual and developmental disabilities to participate in health care decision making', (2018), vol 64(Suppl 2), *Canadian Family Physician Medecin de Famille Canadien*, pp S32-S36.

317 Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Institute, University of Melbourne, 2017; Paul S Appelbaum & Manuel Trachsel, 'The doctrine of informed consent doesn't need modification for supported decision making', (2021), vol 21(11), *The American Journal of Bioethics*, pp 27-29.

318 Carmel Davies, Francesco Fattori, O'Donnell Deirdre, Sarah Donnelly, Shé Éidín Ní, Marie O Shea, Lucia Prihodova, Caoimhe Gleeson, Áine Flynn, Bernadette Rock, Jacqueline Grogan, O'Brien Michelle, O'Hanlon Shane, Marie Therese Cooney, Marie Tighe & Thilo Kroll, 'What are the mechanisms that support healthcare professionals to adopt assisted decision-making practice? A rapid realist review', (2019), vol 19, *BMC Health Services Research*, pp 1-14, 8; see also Kevin De Sabbata & Elena Syurina, *Supported decision-making and dementia*, (Psychiatrie Verlag, 2019); see also Sarah Donnelly, Diarmuid Ó Coimín, Deidre O'Donnell, Éidín Ní Shé, Carmel Davies, Lauren Christophers, Steve Mc Donald & Thilo Kroll, 'Assisted decision-making and interprofessional collaboration in the care of older people: a qualitative study exploring perceptions of barriers and facilitators in the acute hospital setting' (2021) *Journal of interprofessional Care,* pp 1-11

319 Sarah Donnelly, Diarmuid Ó Coimín, Deidre O'Donnell, Éidín Ní Shé, Carmel Davies, Lauren Christophers, Steve Mc Donald & Thilo Kroll, 'Assisted decision-making and interprofessional

collaboration in the care of older people: a qualitative study exploring perceptions of barriers and facilitators in the acute hospital setting' (2021) *Journal of interprofessional Care,* pp 1-11

320 Sarah Donnelly, Diarmuid Ó Coimín, Deidre O'Donnell, Éidín Ní Shé, Carmel Davies, Lauren Christophers, Steve Mc Donald & Thilo Kroll, 'Assisted decision-making and interprofessional collaboration in the care of older people: a qualitative study exploring perceptions of barriers and facilitators in the acute hospital setting', (2021), *Journal of interprofessional Care,* pp 1-11

321 See eg, *Powers of Attorney Act 1998* (Qld).

322 Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, Melbourne Social Equity Insitute, University of Melbourne, 2017; Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, 'Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners', (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826-33; Sarah Donnelly, Diarmuid Ó Coimín, Deidre O'Donnell, Éidín Ní Shé, Carmel Davies, Lauren Christophers, Steve Mc Donald & Thilo Kroll, 'Assisted decision-making and interprofessional collaboration in the care of older people: a qualitative study exploring perceptions of barriers and facilitators in the acute hospital setting', (2021,) *Journal of interprofessional Care,* pp 1-11]

323 Deirdre O'Donnell, Éidín Ní Shé, Carmel Davies, Sarah Donnelly, Therese Cooney, Diarmuid O'Coimin, Diarmuid O'Shea, Lorraine Kyne, Diarmaid O'Sullivan, Bernadette Rock, Marie O'Shea, Eilish McAuliffe, Ann O'Shaughnessy & Thilo Kroll, 'Promoting assisted decision-making in acute care settings for care planning purposes: Study protocol', (2018), vol 1, *HRB Open Research*, 2 https://doi.org/10.12688/hrbopenres.12797.1

324 Lisa Brophy, Renata Kokanovic, Jacinthe Flore, Bernadette McSherry & Helen Herrman, 'Community treatment orders and supported decision-making', (2019), vol 10, *Frontiers in Psychiatry*, 414:1-12.

325 Devora Shapiro, Lauren R Sankary & Paul J Ford, 'Reconciling supported decision making with shared decision making in the context of potential vulnerability', (2021), vol 21(11), *The American Journal of Bioethics*; Karen Strickland, Kasia Bail, Sarah Cope, Murray Turner & Cameron Moss, 'Supported decision-making to assist older persons experiencing elder abuse: an integrative review', (2021), vol 28(4), *Collegian*, pp 447-55; Kevin T Mintz & David C. Magnus, 'Disability, aging, and the importance of recognizing social supports in medical decision making', (2021), vol 21 (11), *The American Journal of Bioethics*, pp 1-3.

326 Alison Picton, 'Decision-making support for inpatients with learning disabilities', (2011), vol 107(32-33), *Nursing Times*, pp 12-14.

327 Ben White, Lindy Willmott, Colleen Cartwright, Malcolm Parker & Gail Williams, (2014), vol 201(4) 'Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment', *Medical Journal of Australia*, pp 229-32; Ben White, Lindy Willmott, Colleen Cartwright, Malcolm Parker & Gail Williams, 'Knowledge of the law about withholding or withdrawing life-sustaining treatment by intensivists and other specialists', (2016), vol 18(2), *Critical Care and Resuscitation*, pp 109-115.

328 Dianne Winkler, Libby Callaway, Sue Sloan & Nadine Holgate, 'Everyday choice making: outcomes of young people with acquired brain injury after moving from residential aged care to community-based supported accommodation', (2015), vol 16(3), *Brain impairment*, pp 221-35.

329 Christine Bigby, Marie Knox, Julie Beadle-Brown, Tim Clement & Jim Mansell, 'Uncovering dimensions of culture in underperforming group homes for people with severe intellectual disability', (2012), vol 50(6), *Intellectual and Developmental Disabilities*, pp 452-67.

330 Michelle Jennett Browning, 'Developing an Understanding of Supported Decision-Making Practice in Canada: The Experiences of People with Intellectual Disabilities and Their Supporter', PhD Thesis, La Trobe University, 2018; Nandini Devi, Birgit Prodinger, Andrew Pennycott, Roja Sooben & Jerome Bickenbach, 'Investigating supported decision-making for persons with mild to moderate intellectual disability using institutional ethnography', (2020), vol 17(2), *Journal of Policy and Practice in Intellectual Disabilities*, pp 143-56.

331 Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney,

'The temporalities of supported decision-making by people with cognitive disability,' (2020), *Social &Cultural Geography*, pp 14, DOI: 10.1080/14649365.2020.1829689

332 Kristin Björnsdóttir, Guðrún V Stefánsdóttir & Ástríður Stefánsdóttir, ''It's my life': autonomy and people with intellectual disabilities', (2015), vol 19(1), *Journal of Intellectual Disabilities*, pp 5-21.

333 Patrick McKearney, 'What escapes persuasion: why intellectual disability troubles 'dependence' in liberal societies', (2021), vol 40 (2), *Medical Anthropology*, pp 155-68.

334 Eileen Baldry, Melissa Clarence, Leanne Dowse & Julian Trollor, 'Reducing vulnerability to harm in adults with cognitive disabilities in the Australian criminal justice system', (2013), vol 10(3), *Journal of Policy and Practice in Intellectual Disabilities*, pp 222-9.

335 Office of the Public Advocate (Vic), *Decision Time: Activating the rights of adults with cognitive disability*, *Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, 2021.

336 Anna Arstein-Kerslake, 'Introduction to criminal responsibility' in Eilionoir Flynn, Anna Arstein-Kerslake, Clíona De Bhailís & Maria Laura Serra (ed) *Global perspectives on legal capacity reform: Our voices, our stories*, Routledge, 2018, pp 19-21; Tina Minkowitz, *Norms and implementation of CRPD Article 12,* September 18, 2010), available at SSRN: https://ssrn.com/abstract=2037452 or http://dx.doi.org/10.2139/ssrn.2037452, 2020.

337 Brigit Merfin-Veitch, *Exploring article 12 of the United Nations Convenion on the Rights of Persons with Disabilities: an integrative literature review*, Donald Beasley Institute, 2016; Peter Bartlett, 'At the interface between paradigms: English mental capacity law and the CRPD', (2020), vol 11, *Frontiers in Psychiatry*, doi: 10.3389/fpsyt.2020.570735

338 Fleur Beaupert & Linda Steele, *Comments on Draft General Comment on Article 12 of the Convention. Submitted to the United Nations Committee on the Rights of Persons with Disabilities*, 2014, p 6; Office of the Public Advocate (Vic), *Decision Time: Activating the rights of adults with cognitive disability, Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, (2021).

339 Piers Gooding, Bernadette McSherry & Anna Arstein-Kerslake, 'Supported decision-making in criminal proceedings: A sociolegal empirical study', (2021), vol 1-11, *Journal of Disability Policy Studies*, pp 1-11.

340 Piers Gooding, Bernadette McSherry & Anna Arstein-Kerslake, 'Supported decision-making in criminal proceedings: A sociolegal empirical study', (2021), vol 1-11, *Journal of Disability Policy Studies*, pp 1-11, 9.

341 Piers Gooding, Bernadette McSherry & Anna Arstein-Kerslake, 'Supported decision-making in criminal proceedings: A sociolegal empirical study', (2021), vol 1-11, *Journal of Disability Policy Studies*, pp 1-11.

342 Amita Dhanda & Gabor Gombos, 'Questions of criminal culpability and persons with disabilities' in Eilionoir Flynn, Anna Arstein-Kerslake, Clíona De Bhailís & Maria Laura Serra (ed) *Global perspectives on legal capacity reform: Our voices, our stories*, Routledge, 2018, pp 32-42.

343 Office of the Public Advocate (Vic), *Decision Time: Activating the rights of adults with cognitive disability*, *Report prepared for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, (2021), pp vii, 11-12.

344 See article 12 heading and (1)(2) CRPD – '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'.

345 Jonathon Savery, 'Voting rights and intellectual disability in Australia: an illegal and unjustified denial of rights', (2015), vol 37(2), *The Sydney Law Review*, pp 287-300; K Nadakavukaren Schefer, Terry Carney, R Cera, J Curran, S De Dycker, V Kühnel, J Lespérance, M Schulze, A Vasquez, C Viennet & H Westermark, *Persons with disabilities' right to autonomy and their right to vote: Australia, Austria, Canada, France, Germany, Italy, the Netherlands, New Zealand, Norway, Spain, Sweden, United Kingdom, United States*, Swiss Institute of Comparative Law, 2019.

346 Section 93(8)(a) *Commonwealth Electoral Act 1918* (Cth).

347 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, 2014.

348 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, 2014.

349 Christine Bigby, Sophia Tipping, Emma Bould & Rebecca Thiele, *Final report: Strategies to support people with intellectual disabilities to participate in voting*, Living with Disability Research Centre, La Trobe University, 2019.

350 Nola M Ries, Elise Mansfield & Rob Sanson-Fisher, 'Ethical and legal aspects of research involving older people with cognitive impairment: A survey of dementia researchers in Australia', (2020), vol 68, *International Journal of Law and Psychiatry*, p 101534.

351 Barbara E Bierer, Ari Ne'eman, Willyanne DeCormier Plosky, David H Strauss, Benjamin C. Silverman & Michael Ashley Stein, 'Integrating Supported Decision-Making into the Clinical Research Process', (2021), vol 21(11), *The American Journal of Bioethics*, pp 32-5.

352 Barbara E. Bierer, Ari Ne'eman, Willyanne DeCormier Plosky, David H Strauss, Benjamin C. Silverman & Michael Ashley Stein, 'Integrating Supported Decision-Making into the Clinical Research Process', (2021), vol 21(11), *The American Journal of Bioethics*, pp 32-5; Camillia Kong, Efrem Mehret & Megan Campbell, 'Education versus screening: the use of capacity to consent tools in psychiatric genomics', (2020), vol 46(2), *Journal of Medical Ethics*, pp 137-42.

353 National Health and Medical Research Council, Australian Research Council & Universities Australia, *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*, National Health and Medical Research Council, 2007, [5.2.17].

354 National Health and Medical Research Council, Australian Research Council & Universities Australia, *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*, National Health and Medical Research Council, 2007, [4.3.2]

355 Nola M Ries, Elise Mansfield & Rob Sanson-Fisher, 'Ethical and legal aspects of research involving older people with cognitive impairment: A survey of dementia researchers in Australia', (2020), vol 68, *International Journal of Law and Psychiatry*, p 101534; Scott Y H Kim, Jason H Karlawish, H Myra Kim, Ian F Wall, Andrea C Bozoki & Paul S Appelbaum, 'Preservation of the capacity to appoint a proxy decision maker: Implications for dementia research', (2011), vol 68(2), *Archives of General* Psychiatry, pp 214-20; Nola Ries & Elise Mansfield, 'Advance research directives: dementia researchers' views on a prototype directive and implementation strategies', (2021), vol 43(3), *Ethics & Human Research*, pp 10-25.

356 Nola M Ries, Elise Mansfield & Rob Sanson-Fisher, 'Ethical and legal aspects of research involving older people with cognitive impairment: a survey of dementia researchers in Australia', (2020), vol 68, *International Journal of Law and Psychiatry*, 101534.

357 Barbara E Bierer, Ari Ne'eman, Willyanne DeCormier Plosky, David H Strauss, Benjamin C Silverman & Michael Ashley Stein, 'Integrating Susported decision-making into the clinical research process', (2021), vol 21(11), *The American Journal of Bioethics*, pp 32-5.

358 Theresa S Wied, Aiufe Poth, Johannes Pantel, Frank Oswald & Julia Haberstroh, 'How do dementia researchers view support tools for informed consent procedures of persons with dementia?', (2020), *Zeitschrift Fur Gerontologie Und Geriatrie*, 1-9, 8 doi.org/10.1007/s00391-020-01779-2

359 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, 2014; New South Wales Law Reform Commission, *Review of the Guardianship Act 1987: Report No.145*, 2018; Victorian Law Reform Commission, *Guardianship: Final Report*, 2012; ACT Law Reform Advisory Council, *Guardianship Report*, 2016; Tasmanian Law Reform Institute, *Review of the Guardianship and Administration Act 1995 (Tas)*, Final Report No 26, December 2018.

360 Shih-Ning Then, Terry Carney, Christine Bigby & Jacinta Douglas, 'Supporting decision-making of adults with cognitive disabilities: the role of law reform agencies – recommendations, rationales and influence', (2018), vol 61, *International Journal of Law and Psychiatry*, pp 64-75; Willene Holness, 'Equal recognition and legal recognition and legal capacity for persons with disabilities: Incorporating the principle of proportionality', (2014), vol 30, *South African Journal on Human Rights*, pp 313-44.

361 Human Rights Council, *Report of the Special Rapporteur on the rights of persons with disabilities*, 37th sess, Agenda Item 3, UN Doc A/HRC/37/56 (12 December, 2017).

362 Jonathan Martinis, Jason Harris, Dean Fox & Peter Blanck, ‘State guardianship laws and supported decision-making in the United States after Ross and Ross v Hatch: analysis and implications for research, policy, education, and advocacy’, (2021), *Journal of Disability Policy Studies*; Nina A Kohn, ‘Realizing supported decision-making: What it does—and does not—require’, (2021), vol 21(11), *The American Journal of Bioethics*, pp 313-56; see also L VanPuymbrouck, *Supported Decision Making in the United States: A White Paper*, Council on Quality and Leadership, 2017 https://www.c-q-l.org/wp-content/uploads/2019/12/CQL-2017-White-Paper-Supported-Decision-Making-In-The-US.pdf

363 Rebecca Naomi Davies, Shirli Werner & Amanda Sinai, ‘Guardianship and supported decision-making in israel’, (2017), vol 11(2), *Advances in Mental Health and Intellectual Disabilities*, pp 54-64; Michael Schindler & Meytal Segal-Reich, ‘Supported decision-making for older persons in Israel: the 2015 precedent and the following 2016 regulation’, (2016), vol 10, *Elder law review (University of Western Sydney)*, pp 1-21; Roni Holler, Shirli Werner, Yotab Tolum & Miriam Pomerantz, ‘Choice within the Israeli welfare state: lessons learned from legal capacity housing services’ in Roger J Stancliffe, Michael L Wehmeyer, Karrie J Shogren & Brian H Abery (ed) *Choice, preference, and disability: Promoting self-determination across the lifespan*, Springer, 2020.

364 Arlene S Kanter & Yotam Tolub, ‘The fight for personhood, legal capacity, and equal recognition under the law for people with disabilities in Israel and beyond’, (2017), vol 39(2), *Cardozo Law Review*, pp 557-610.

365 Scottish Mental Health Law Review, *Interim Report*, July 2021.

366 Kristin Booth Glen, ‘Introducing a new human right: learning from others, bringing legal capacity home’, (2018), vol 49(3), *Columbia Human Rights Law Review*, pp 1-96, 20.

367 Terry Carney, ‘Participation and service access rights for people with intellectual disability: a role for law?’, (2013), vol 38(1), *Journal of Intellectual & Developmental Disability*, pp 59-69; Shih-Ning Then, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1), *Sydney Law Review*, pp 133-66.

368 Christine Bigby, Jacinta Douglas, Terry Carney, Shih-Ning Then, Ilan Wiesel & Elizabeth Smith, ‘Delivering decision making support to people with cognitive disability - what has been learned from pilot programs in Australia from 2010 to 2015’, (2017), vol 52(3), *Australian Journal of Social Issues*, pp 222-40, 231-2.

369 Christine Bigby, Mary Whiteside & Jacinta Douglas, *Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas*, Living with Disability Research Centre, La Trobe University, 2015, pp 5; Terry Carney & Fleur Beaupert, ‘Public and private bricolage: challenges balancing law, services and civil society in advancing the CRPD supported decision making’, (2013), vol 36(1), *University of New South Wales Law Journal*, pp 175-201; Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A real bucket of worms”: views of people living with dementia and family members on supported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587-608.

370 Hope Davidson, ‘The *Assisted Decision-Making (Capacity) Act 2015*: how will it change healthcare decision making for people with dementia’, (2016), vol 23(2), *Medico-Legal Journal of Ireland*, pp 62-9, 67.

371 Nina A Kohn & Jeremy A Blumenthal, ‘A critical assessment of supported decision-making for persons aging with intellectual disabilities’, (2014), vol 7(1, Supplement), *Disability and Health Journal*, p S40.

372 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014).

373 See eg, Tina Minkowitz, ‘CRPD Article 12 and the Alternative to Functional Capacity: Preliminary Thoughts Towards Transformation’, (2013); also note that revelations of neglect and abuse by adult guardians has received significant and much justified attention in the US: AAP (1987) *Guardians of the Elderly: An ailing system,* American Associated Press. https://apnews.com/article/1198f64bb05d9c1ec690035983c02f9f

374 *Mental Capacity Act 2005* (England and Wales).

375 Kristin Booth Glen, ‘The perils of guardianship and the promise of supported decision making’, (2014), vol 48(1-2), *Clearinghouse Review*, pp 17-22.

376 Ben White, Lindy Willmott & Shih-Ning Then, ‘Chapter 7: Adults who lack capacity: substitute decision Making’ in Ben White, Fiona Mcdonald & Lindy Willmott (ed) *Health Law in Australia*, Lawbook Co, 2018, pp 207-70.

377 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report* , 2014.

378 See: *Guardianship and Administration Act 2000* (Qld) s11B ‘General principles’; *Powers of Attorney Act 1998* (Qld) s 6C (General principles); *Guardianship and Administration Act 1993* (SA) s 5(c); *Guardianship of Adults Act 2016* (NT) s 11(2)(e); *Guardianship and Administration Act* (Tas) s 20(1)(b); *Guardianship and Administration Act 1990* (WA) s 4(4).

379 Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’ (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174

380 Ben White, Lindy Willmott & Shih-Ning Then, ‘Chapter 7: Adults who lack capacity: substitute decision making’ in Ben White, Fiona McDonald & Lindy Willmott (ed) *Health Law in Australia*, Lawbook Co, 2018, pp 207-70.

381 Bizchut (The Israeli Human Rights Center for People with Disabilities), *Supported Decision-Making Service for Persons with Disabilities: Service Model*, Bizchut, 2016.

382 Christine Bigby, Jacinta Douglas & Elizabeth Smith, *Considering human rights in decision making: Evaluation of the introduction of structured decision making framework in the Public Trustee Queensland*, Living with Disability Research Centre, La Trobe University, 2021.

383 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014); Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014).

384 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014), [17].

385 Terry Carney & Shih-Ning Then, ‘Support for decision-making as people age with a cognitive impairment’ in Michelle Putnam & Christine Bigby (ed) *Handbook on Ageing with Disability*, Routledge, 2021, pp 186-95; Craig Sinclair, Kate Gersbach, Michelle Hogan, Romola S Bucks, Kirsten A Auret, Josephine M Clayton, Meera Agar & Sue Kurrle, ‘How couples with dementia experience healthcare, lifestyle, and everyday decision-making’, (2018), vol 30(11), *International psychogeriatrics*, pp 1639-47.

386 Terry Carney, ‘Adult guardianship and other financial planning mechanisms for people with cognitive impairment in Australia’ in L Ho & R Lee (ed) *Special Needs Financial Planning: A Comparative Perspective*, Cambridge University Press, 2019, pp. 3-29.

387 Michael Schindler & Meytal Segal-Reich, ‘Supported decision-making for older persons in Israel: the 2015 precedent and the following 2016 regulation’, (2016), vol 10, *Elder Law Review (University of Western Sydney)*, pp 1-21, 9.

388 Shih-Ning Then, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1), *Sydney Law Review*, pp 133-66.

389 *Guardianship and Administration Act 2000* (Qld) s 11B, Principle 10; *Powers of Attorney Act 1998* (Qld), s 6C, Principle 10. See also *Guardianship of Adults 2016* (NT), s 4(4)(b).

390 *Mental Capacity Act 2005* (England and Wales), s 1(3). See Rosie Harding, ‘Care and relationality: supported decision-making under the UN CRPD’ in Rosie Harding R, R Fletcher & C Beasley (ed) *Revaluing Care in Theory, Law and Policy: Cycles and Connections*, Routledge, 2017.

391 Alison Picton, ‘Decision-making support for inpatients with learning disabilities’, (2011), vol 107(32-33), *Nursing Times*, pp 12-14; Rosie Harding & Taşcıoğlu Ezgi,’Supported decision-making from theory to practice: Implementing the right to enjoy legal capacity’, (2018), vol 8(2), *Societies (Basel, Switzerland)* doi:10.3390/soc8020025; Rosie Harding, ‘Legal constructions of dementia: discourses of autonomy at the margins of capacity’, (2012), vol 34 (4), *The Journal of Social Welfare & Family Law*, pp 425-42; Peter Bartlett, ‘At the interface between paradigms:

English mental capacity law and the CRPD', (2020), vol 11, *Frontiers in Psychiatry*, doi: 10.3389/fpsyt.2020.570735; Julie Beadle-Brown, 'Supported decision-making in the United Kingdom: lessons for Future Success', (2015), vol 2 (1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 17-28.

392 Nina A Kohn, 'Realizing supported decision-making: what it does—and does not—require', (2021), vol 21(11), *The American Journal of Bioethics*, p 313-56.

393 Volker Lipp & Julian O Winn, 'Guardianship and autonomy: foes or friends?', (2011), vol 5, *Journal of International Aging, Law & Policy*, pp 41-56.

394 *Medical Treatment Planning and Decisions Act 2016* (Vic); *Guardianship and Administration Act 2019* (Vic); see Office of the Public Advocate (Vic), 'Side by Side: A guide for people wanting support to make decisions' (2018); Office of the Public Advocate (Vic), 'Supported Decision-Making in Victoria' (2020)

395 *Decision-making, Support and Protection to Adults Act 2003* (Y); See Shih-Ning Then, 'Evolution and innovation in guardianship laws: assisted decision-making', (2013), vol 35(1), *Sydney Law Review*, pp 133-66.

396 *Civil Code 1991* (Q).

397 Kristin Booth Glen, 'Introducing a new human right: learning from others, bringing legal capacity home', (2018), vol 49(3), *Columbia Human Rights Law Review*, pp 1-96, 29; Dalun Zhang, Jessica M Walker, Dianey R Leal, Leena Jo Landmark & Antonis Katsiyannis, 'A Call to Society for Supported Decision-Making: Theoretical and Legal Reasoning', (2019), vol 28(7), *Journal of Child and Family Studies*, pp 1803-14.

398 *Assisted Decision-Making (Capacity) Act 2015* (Ireland).

399 *Assisted Decision-Making (Capacity) Act 2015* (Ireland); Arlene S Kanter & Yotam Tolub, 'The fight for personhood, legal capacity, and equal recognition under the law for people with disabilities in Israel and beyond', (2017), vol 39(2), *Cardozo Law Review*, pp 557-610; Marie Fallon-Kund & Jerome E. Bickenbach, 'New legal capacity laws and the United Nations Convention on the Rights of Persons with Disabilities: an overview of five countries in Europe', (2017), vol 24(3), *European Journal of Health Law*, pp 285-310; European Institute of National Human Rights Institutions (ENNHRI) and Mental Health Europe, 'Implementing supported decision-making, Developments across Europe and the role of National Human Rights Institutions' (8 June 2020)./ennhri.org/news-and-blog/implementing-supported-decision-making-for-people-with-disabilities-new-report-shows-developments-in-europe-and-the-role-of-nhris/?msclkid=86e07153cf3911eca8d523f661e4cd34; de Sande, C A, Ros, B F, i Chavero, J M S, Marroyo, L, Leotti, P, Karagouni, S, Hänninen, K & J Churchill (I-DECIDE Partnership), *From "guardians" to "supporters": supported decision-making in service provision for persons with disabilitie*s, 2018

400 Terry Carney, 'Guardianship, 'social' citizenship and theorising substitute decision-making law' in Israel Doron & Ann M Soden (ed) *Beyond elder law: new directions in law and aging,* Springer Berlin Heidelberg, 2012, pp 1-17.

401 *Assisted Decision-Making (Capacity) Act 2015* (Ireland) s 10; Nina A Kohn, 'Legislating supported decision-making', (2021), vol 58(2), *Harvard Journal on Legislation,* pp 317-8; Canadian Centre for Elder Law, *Study Paper on Inclusive Investing: Respecting the Rights of Vulnerable Investors through Supported Decision-Making*, 2021; Kristin Booth Glen, 'Supported decision-making from theory to practice: further reflections on an intentional pilot project', (2020), vol 13, *Albany Government Law Review*, pp 94-168

402 Antonio Martinez-Pujalte, 'Legal capacity and supported decision-making: lessons from some recent legal reforms', (2019), vol 8(4), *Laws*, 16 doi:10.3390/laws8010004

403 Antonio Martinez-Pujalte, 'Legal capacity and supported decision-making: lessons from some recent legal reforms', (2019), vol 8(4), *Laws*, doi:10.3390/laws8010004

404 Charles O'Mahony & Catriona Maloney, 'The impact of international human rights law on Irish mental health and mental capacity law reform' (2017) 23 *Medico-Legal Journal of Ireland* 24.

405 *Adult Guardianship and Trusteeship Act 2008* (A); *Assisted Decision-Making (Capacity) Act 2015* (Ireland).

406 Nina A Kohn, Jeremy A Blumenthal & Amy T Campbell, 'Supported decision making: a viable alternative to guardianship? (Capacity, conflict and change: elder law and estate planning themes in an aging world)' (2013) 117(4) *Penn State Law Review* 1111

407 Hope Davidson, ‘The *Assisted Decision-Making (Capacity) Act 2015*: how will it change healthcare Decision making for people with dementia’, (2016), vol 23(2) *Medico-Legal Journal of Ireland* 62.

408 Victorian Law Reform Commission, *Guardianship: Final Report*, 2012. ACT Law Reform Advisory Council, *Guardiansihp Report*, 2016; see also Shih-Ning Then, Terry Carney, Christine Bigby & Jacinta Douglas, ‘Supporting decision-making of adults with cognitive disabilities: the role of law reform agencies – recommendations, rationales and influence’, (2018), vol 61, *International Journal of Law and Psychiatry*, pp 64-75.

409 Shih-Ning Then, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1), *Sydney Law Review*, pp 133-66.

410 Shih-Ning Then, Hilary Patrick & Nicola Smith, ‘Reinforcing guardianship regimes through assisted decision making - a Scottish perspective’ (2014)(4) *The Juridical Review*, pp 263-80.

411 *Representation Agreement Act*, BC 1996, c 405; Tim Stainton, ‘Supported decision-making in Canada: Principles, policy, and practice’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 1-11.

412 Shih-Ning Then, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1), *Sydney Law Review*, 133-66; *Representation Agreement Act 1996* (BC).

413 For some discussion of how these work in practice see: Nidus Personal Planning Resource Centre and Registry, *Experiences of Adults Living with Fetal Alcohol Spectrum Disorder and their Personal Supporters in Making and Using a Representation Agreement* http://www.nidus.ca/PDFs/Nidus_Research_RA_FASD_Project.pdf

414 André Bzdera, *Supported Decision-Making Replaces Adult Guardianship in Austria*, (2019).

415 André Bzdera, *Supported Decision-Making Replaces Adult Guardianship in Austria*, (2019).

416 *Guardianship and Administration Act 2019* (Vic) part 4

417 Renato Antonio Constantino Caycho, ‘The flag of imagination: Peru’s new reform on legal capacity for persons with intellectual and psychosocial disabilities and the need for understandings in private law’, (2020), vol 14 (June), *The Age of Human Rights Journal*, pp 155-80.

418 Antonio Martinez-Pujalte, ‘Legal Capacity and Supported Decision-making: Lessons from some Recent Legal Reforms’, (2019), vol 8(4), *Laws*, pp 11, doi:10.3390/laws8010004

419 Therése Fridström Montoya, *Supported decision-making in Swedish law – Is the »God Man« a good or bad guy in light of the CRPD?*, Psychiatrie Verlag, 2019.

420 Therése Fridström Montoya, *Supported decision-making in Swedish law – Is the »God Man« a good or bad guy in light of the CRPD?*, PsychiatrieVerlag, 2019.

421 Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015, pp 17.

422 Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015.

423 Tim Stainton, ‘Supported decision-making in Canada: Principles, policy, and practice’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 1-11.

424 David Plater, Lukas Price, Esther Richards & Mark Giancaspro, ‘New avenues of providing effective care: the role of microboards’, (2021), vol 43 (6), *The Bulletin: The Law Society of South Australia Journal*, pp 9-11.

425 Tim Stainton, ‘Supported decision-making in Canada: Principles, policy, and practice’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 1-11.

426 Michelle Jennett Browning, ‘Developing an understanding of supported decision-making practice in Canada: The experiences of people with intellectual disabilities and their supporter’, PhD Thesis, La Trobe University, 2018, pp 101.

427 David Plater, Lukas Price, Esther Richards & Mark Giancaspro, ‘New avenues of providing effective care: the role of microboards’, (2021), vol 43(6), *The Bulletin: The Law Society of South Australia Journal*, pp 9-11; Circles of Support and Microboards (COSAM), *Research and evaluation summary: academic research and professional evaluation of circles of support and microboards*, COSAM, nd. https://supporteddecisionmaking.com.au/wp-content/uploads/sites/4/2022/02/Research-and-Evaluation-Summary-Academic-Research-and-Professional-Evaluation-of-COSAM-Final.pdf

428 Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015, pp 20-29.

429 Nina A Kohn, Jeremy A Blumenthal & Amy T Campbell, 'Supported decision making: A viable alternative to guardianship? (2013), vol 11(4), *Penn State Law Review*, pp 1111-58; Canadian Institute for Inclusion and Citizenship University of British Columbia, *Microboards, Social Capital and Quality of Life: Final Report of a two year qualitative inquiry*, (Canadian Institute for Inclusion and Citizenship, University of British Columbia, 2020).

430 Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015 at 39-51.

431 Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015 at 98-99.

432 See eg, Nanette Elster & K Parsi, 'Transitioning from adolescence to adulthood with autism spectrum disorder: An overview of planning and legal Issues', (2020), vol 43(4), *Psychiatric Clinics of North America*; Disability Voices United, *With Support and without the Court: Supported Decision-Making Handbook for Parents of Adults with Developmental Disabilities in California*, (2020).

433 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014).

434 Sascha Callaghan & Christopher James Ryan, 'An evolving revolution: evaluating Australia's compliance with the "Convention on the Rights of Persons with Disabilities" in mental health law', (2016) *University of New South Wales Law Journal* 39 (2), pp 596-624.

435 Jill Stavert, 'Supported decision-making and paradigm shifts: word play or real change?', (2020), vol 11, *Frontiers in Psychiatry*, pp 571005-571005; Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014).

436 Ulrika Järkestig Berggren, 'The Swedish Personal Ombudsman: support in decision-making and accessing human rights' in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 230-43.

437 Ulrika Järkestig Berggren, 'The Swedish Personal Ombudsman: support in decision-making and accessing human rights' in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 230-43, 230.

438 Fiona Morrissey, 'The United Nations Convention on the Rights of Persons with Disabilities: a new approach to decision-making in mental health law', (2012), vol 19(5), *European Journal of Health Law*, pp 423-40.

439 Piers Gooding, *A new era for mental health law and policy: supportive decision-making and the UN Convention on the Rights of Persons with Disabilities*, Cambridge University Press, 2017, pp 187-9

440 Ulrika Järkestig Berggren, 'The Swedish Personal Ombudsman: support in decision-making and accessing human rights' in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 230-43.

441 Ulrika Järkestig Berggren, 'The Swedish Personal Ombudsman: support in decision-making and accessing human rights' in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 230-43, 240-1.

442 Eg, European Union Agency for Fundamental Rights, *Choice and control: the right to independent living: Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States*, (2012); Piers Gooding & Elionoir Flynn, 'Querying the call to introduce mental capacity testing to rights-based mental health law', (2015), vol 4(2), *Laws*, pp 245-71.

443 Heléne Combrinck & Enoch Chilemba, ''The revolution will not be televised': recent developments in mental health law reform in Zambia and Ghana' in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 184-98.

444 Richard M Duffy & Brendan D Kelly, 'India's Mental Healthcare Act, 2017: content, context, controversy', (2019), vol 62, *International Journal of Law and Psychiatry*, pp 169-78; Soumitra Pathare & Arjun Kapoor, 'Decisional autonomy and India's Mental Healthcare Act, 2017: A comment on emerging jurisprudence' in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 155-70; Mukul Inamdar, Michael Ashley Stein & Joske Bunders, 'Does "supported decision-making" in India's Mental Health Care Bill, 2013, measure up to the CRPD's standards?', (2016), vol 1, *Indian Journal of Medical Ethics*, pp 229-36.

445 Nikita V Alexandrov & Natalie Schuck, 'Coercive interventions under the new Dutch mental health law: towards a CRPD-compliant law?', (2021), vol 76, *International Journal of Law and Psychiatry*, pp 101685-101685.

446 Chris Maylea, Ann Jorgensen, Sarah Matta, Katherine Ogilvie & Paul Wallin, 'Consumers' experiences of mental health advance statements', (2018), vol 7(22), *Laws*, doi:10.3390/laws7020022

447 Department of Health State of Victoria, *Mental Health and Wellbeing Act: Update and engagement paper*, (State of Victoria, Department of Health, June 2021).

448 Chris Maylea, Ann Jorgensen, Sarah Matta, Katherine Ogilvie & Paul Wallin, 'Consumers' experiences of mental health advance statements', (2018), vol 7(22), *Laws*, doi:10.3390/laws7020022

449 Chris Maylea, Ann Jorgensen, Sarah Matta, Katherine Ogilvie & Paul Wallin, 'Consumers' experiences of mental health advance statements', (2018), vol 7(22), *Laws*, pp 2 doi:10.3390/laws7020022

450 Chris Maylea, Ann Jorgensen, Sarah Matta, Katherine Ogilvie & Paul Wallin 'Consumers' experiences of mental health advance statements', (2018), vol 7(22), *Laws*, doi:10.3390/laws7020022; Mental Welfare Commission for Scotland. *Mental Health Act Monitoring Report 2018–2019*. Edinburgh. Available online at: https://www.mwcscot.org.uk/sites/default/files/2019-10/MHA-MonitoringReport-2019_0.pdf

451 Fiona Morrissey, 'The United Nations Convention on the Rights of Persons with Disabilities: a new approach to decision-making in mental health law', (2012), vol 19(5), *European Journal of Health Law*, pp 423-40.

452 Cath Roper, 'Capacity does not reside in me' in Claire Spivakovsky, Kate Seear & Adrian Carter (ed) *Critical Perspectives on Coercive Interventions*, Routledge, 2018, pp 85-96; Chris Maylea, Ann Jorgensen, Sarah Matta, Katherine Ogilvie & Paul Wallin, 'Consumers' experiences of mental health advance statements', (2018), vol 7(22), *Laws*, doi:10.3390/laws7020022

453 Noting that PADs may be more useful depending on the narrative type taken on by the person at a particular time: Fauzia Knight, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, Kate Johnston-Ataata & Helen Herrman, 'Supported decision-making: the expectations held by people with experience of mental illness', (2018), vol 28(6), *Qualitative Health Research*, pp 1002-15, 1012.

454 Meredith Stone, Renata Kokanovic, Felicity Callard & Alex F Broom, 'Estranged relations: coercion and care in narratives of supported decision-making in mental healthcare', (2020), vol 46(1), *Medical Humanities*, pp 62-72.

455 Meredith Stone, Renata Kokanovic, Felicity Callard & Alex F Broom, 'Estranged relations: coercion and care in narratives of supported decision-making in mental healthcare', (2020), vol 46(1), *Medical Humanities*, pp 62-72.

456 Chris Maylea, Ann Jorgensen, Sarah Matta, Katherine Ogilvie & Paul Wallin, 'Consumers' experiences of mental health advance statements', (2018), vol 7(22), *Laws*, doi:10.3390/laws7020022

457 Philip Sharad, Subhashini Rangarajan, Sydney Moirangthem, Channaveerachari Kumar, Mahesh Gowda, Guru Gowda & Suresh Math, 'Advance directives and nominated representatives: A critique', (2019), vol 61(10), *Indian Journal of Psychiatry*, pp 680-85.

458 Christopher H Maylea, 'A rejection of involuntary treatment in mental health social work', (2017), vol 11(4), *Ethics & Social Welfare*, pp 336-52.

459 *Mental Health Act 2015* (ACT) s 25.

460 Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, ‘Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners’, (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826-33.

461 Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, ‘Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners’, (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826-33.

462 Sascha Callaghan & Christopher James Ryan, ‘An evolving revolution: evaluating Australia’s compliance with the “Convention on the Rights of Persons with Disabilities” in mental health law’, (2016) *University of New South Wales Law Journal* 39 (2), pp 596-624; Soumitra Pathare & Arjun Kapoor, ‘Decisional autonomy and India’s Mental Healthcare Act, 2017: a comment on emerging jurisprudence’ in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 155-70; Mukul Inamdar, Michael Ashley Stein & Joske Bunders, ‘Does “supported decision-making” in India’s Mental Health Care Bill, 2013, measure up to the CRPD’s standards?’, (2016), vol 1, *Indian Journal of Medical Ethics*, pp 229-36; Kanna Sugiura, Faraaz Mahomed, Shekhar Saxena & Vikram Patel, ‘An end to coercion: rights and decision-making in mental health care’, (2020), vol 98(1), *Bulletin of the World Health Organization,* pp 52-8; Renata Kokanovic, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, ‘Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners’, (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826-33; Brophy Lisa, McSherry Bernadette, Renata Kokanovic, Kristen Moeller-Saxone & Helen Herrman, *Guidelines for supported decision-making in mental health services*, University of Melbourne, 2017; Lisa Brophy, Renata Kokanovic, Jacinthe Flore, Bernadette McSherry & Helen Herrman, ‘Community treatment orders and supported decision-making’, (2019), vol 10, Frontiers in Psychiatry, 414:1-12.

463 Soumitra Pathare & Arjun Kapoor, ‘Decisional Autonomy and India’s Mental Healthcare Act, 2017: a comment on emerging jurisprudence’ in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 155-70; Richard M Duffy & Brendan D Kelly, ‘India’s Mental Healthcare Act, 2017: content, context, controversy’, (2019), vol 62, *InternationalJjournal of Law and Psychiatry*, pp 169-78.

464 Cath Roper, ‘Capacity does not reside in me’ in (ed) Claire Spivakovsky, Kate Seear & Adrian Carter *Critical Perspectives on Coercive Interventions*, Routledge, 2018, pp 85-96, 86.

465 Fauzia Knight, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, Kate Johnston-Ataata & Helen Herrman, ‘Supported decision-making: the expectations held by people with experience of mental illness’, (2018), vol 28(6), *Qualitative Health Research*, pp 1002-15.

466 *Medical Treatment Planning and Decisions Act 2016* (Vic) ss 293-295.

467 Jill Stavert, ‘The exercise of legal capacity, supported decision-making and Scotland’s mental health and incapacity legislation: working with CRPD challenges’, (2015), vol 4(2), *Laws*, pp 296-313.

468 *Mental Capacity Act 2005* (England and Wales) ss 35-41.

469 Jill Stavert, ‘The exercise of legal capacity, supported decision-making and Scotland’s mental health and incapacity legislation: working with CRPD challenges’, (2015), vol 4(2), *Laws*, pp 296-313.

470 Neeraj S Gill, John A Allan, Belinda Clark & Alan Rosen, ‘Human rights implications of introducing a new mental health act – principles, challenges and opportunities’, (2020), vol 28(2), *Australasian Psychiatry*, pp 167-70 (describing the Queensland equivalent).

471 Karen Newbigging, Julie Ridley, Mick McKeown, Karen Machin & Konstantina Poursanidou, ‘‘When you haven’t got much of a voice’: an evaluation of the quality of Independent Mental Health Advocate (IMHA) services in England’), (2015), vol 23(3), *Health & Social Care in the Community*, pp 313-324

472 John Dawson & George Szmukler, ‘The ‘fusion law’ proposals and the CRPD’ in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 95-108.

473 *Mental Capacity Act 2016* (Northern Ireland)

474 John Dawson & George Szmukler, ‘The ‘fusion law’ proposals and the CRPD’ in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 95-108.

475 Nina A Kohn, ‘Realizing supported decision-making: what it does—and does not—require’, (2021), vol 21(11), *The American Journal of Bioethics*, pp 313-56.

476 Nina A Kohn, ‘Legislating supported decision-making’, (2021), vol 58(2), *Harvard Journal on Legislation*, pp 313-57.

477 Nina A Kohn, ‘Legislating supported decision-making’, (2021), vol 58(2), *Harvard Journal on Legislation*., pp 313-57, 315; see also Eliana J Theodorou, ‘Supported decision-making in the lone-star tate’, (2018), vol 93(4), *New York University Law Review*, 973-1013; Piers Gooding & Terry Carney, ‘Australia: Lessons from a reformist path to supported decision-making’, (forthcoming).

478 Meredith Stone, Renata Kokanovic, Felicity Callard & Alex F Broom, ‘Estranged relations: coercion and care in narratives of supported decision-making in mental healthcare’, (2020), vol 46(1), *Medical Humanities*, pp 62-72.

479 Terry Carney, ‘Searching for workable alternatives to guardianship for vulnerable populations?’, (2015), vol 1(1), *Ethics, Medicine and Public Health*, pp 113-19; see for example in relation to advance directives: Katherine R Waite, Alex D Federman, Danielle M McCarthy, Rebecca Sudore, Laura M Curtis, David W Baker, Elizabeth A H Wilson, Romana Hasnain-Wynia, Michael S Wolf & Michael K Paasche-Orlow, ‘Literacy and race as risk factors for low rates of advance directives in older adults’, (2013), vol 61(3), *Journal of the American Geriatrics Society (JAGS)*, pp 403-6; Craig Sinclair, K Auret, S F Evans, F Williamson, S Dormer, A Wilkinson, K Greeve, A Koay, D Price & F Brims, ‘Advance care planning uptake among patients with severe lung disease: a randomised patient preference trial of a nurse-led, facilitated advance care planning intervention’, (2017), vol 7(2), *BMJ Open*, e013415-e013415; Craig Sinclair, Marcus Sellars, Kimberly Buck, Karen Detering, Ben White & Linda Nolte, ‘New geriatrics and gerontology findings reported from Austin Health (Association between region of birth and advance care planning documentation among older Australian migrant communities: A multi-center audit study)’, (2020), *Medical Letter on the CDC & FDA*, 1717-1717.

480 Therése Fridström Montoya, *Supported decision-making in Swedish law – Is the »God Man« a good or bad guy in light of the CRPD?*, Psychiatrie Verlag, 2019.

481 Tim Stainton, ‘Supported decision-making in Canada: principles, policy, and practice’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 1-11; Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015.

482 Sheila M Wildeman, ‘Consent to psychiatric treatment: From insight (into illness) to incite (a riot)’ in Colleen Flood & Jennifer Chandler (ed) *Law and mind: Mental health law and policy in Canada*, LexisNexis, 2016.

483 Bruce Alston, ‘Towards supported decision-making: article 12 of the Convention on the rights of persons with disabilities and guardianship law reform’, (2017), vol 35(2), *Law in Context*, pp 21-39, 38.

484 Gavin Davidson, Lisa Brophy, Jim Campbell, Susan J Farrell, Piers Gooding & Ann-Marie O’Brien, ‘An international comparison of legal frameworks for supported and substitute decision-making in mental health services’, (2016), vol 44, *International journal of law and psychiatry*, pp 30-40, 39; see also Shih-Ning Then, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1), *Sydney Law Review*, pp 133-66.

485 Terry Carney & Fleur Beaupert, ‘Public and private bricolage: challenges balancing law, services and civil society in advancing the CRPD supported decision making’, (2013), vol 36(1), *University of New South Wales Law Journal*,pp 175-201; Shih-Ning Then, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1), *Sydney Law Review*, pp 133-66.

486 Terry Carney, ‘Supported decision-making for people with cognitive ipairments: An Australian prspective?’, (2015), vol 4, *Laws*, pp 37-59; Terry Carney, ‘Supporting people with cognitive disabilities with decision-making: any Australian law reform contributions?’, (2015), vol 2(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 6-16.

487 Tim Stainton, ‘Supported decision-making in Canada: principles, policy, and practice’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 1-11.

488 Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law*, Law Commission of Ontario, 2015, pp 100.

489 Lucy Series & Anna Nilsson, ‘Article 12 CRPD: equal Recognition before the Law’ in I Bantekas, M A Stein & D Anastasiou (ed) *The UN Convention on the Rights of Persons with Disabilities: a commentary*, Oxford University Press, 2018, pp 340-79.

490 Canadian Centre for Elder Law, *Study Paper on Inclusive Investing: Respecting the Rights of Vulnerable Investors through Supported Decision-Making*, 2021.

491 See Piers Gooding & Terry Carney, ‘Australia: lessons from a reformist path to supported decision-making’ (forthcoming).

492 Terry Carney, ‘Guardianship, ‘social’ citizenship and theorising substitute decision-making law’ in Israel Doron & Ann M Soden (ed) *Beyond elder law: new directions in law and aging,* Springer Berlin Heidelberg, 2012, pp 1-17.

493 Other examples include: L Duffield, S Koritsas, J Watson & N Hagiliassis, ‘Decision-making support for people with cognitive disability. A guide for disability workers’ Melbourne Scope (Aust) (2016); IHC New Zealand, ‘Supporting Decision-Making. A Guide for Supporters of people with Intellectual Disability’ (20xx) https://ihc.org.nz/sites/default/files/documents/10007_1511_SupportedDecisionMaking_Resource_V4.3_WEB_0.pdf; NSW Government Department of Family & Community Services (FACS), ‘Supported Decision-making. A handbook for facilitators’ (2019) https://www.ideas.org.au/books/supported-decision-making-a-handbook-for-facilitators.html; Victorian Government Department of Human Services (DHS), ‘Supporting decision-making. A guide to supporting people with a disability to make their own decisions’, (2012); Western Australia’s Individualised Services (WAIS), ‘Supported Decision-making’ (20xx) https://waindividualisedservices.org.au/wp-content/uploads/2019/02/WAIS0008_4-Booklets-in-One-May15.pdf; IHC New Zealand, ‘Supporting Decision-Making. A Guide for Supporters of people with Intellectual Disability’ (20xx) https://ihc.org.nz/sites/default/files/documents/10007_1511_SupportedDecisionMaking_Resource_V4.3_WEB_0.pdf

494 Carmelle Peisah, Oluwatoyin A Sorinmade, Leander Mitchell & Cees M P M Hertogh, ‘Decisional capacity: toward an inclusionary approach’, (2013), vol 25(10), *International Psychogeriatrics*, pp 1571-79.

495 Mark Jayes, Lynn Austin & Laura J E Brown, ‘Supported decision-making and mental capacity assessment in care homes: A qualitative study’, (2020), *Health & Social Care in the Community,* 00:1–9.

496 American Bar Association, *Practical Tool for Lawyers: Steps in Supported Decision-Making*, (2016).

497 See: Disability Voices United, *With Support and without the Court: Supported Decision-Making Handbook for Parents of Adults with Developmental Disabilities in California* (2020), SDM-Handbook_Oct2020.6.pdf (disabilityvoicesunited.org)

498 See, eg, Kate Fulton & Leanne Pearman, *Supported Decision Making*, Western Australia’s Individualised Services, undated; Craig Sinclair, Kate Gersbach, Michelle Hogan, Romola S Bucks, Kirsten A Auret, Josephine M Clayton, Meera Agar & Sue Kurrle, ‘How couples with dementia experience healthcare, lifestyle, and everyday decision-making’, (2018), vol 30 (11), *International Psychogeriatrics*, pp 1639-47.

499 Karrie A Shogren, Graham G Rifenbark, Michael L Wehmeyer, Evan E Dean, Mary B Killeen & Judith Karsevar, ‘Refining the supported decision making inventory’, (2020), vol 17(3), *Journal of Policy and Practice in Intellectual Disabilities*, pp 195-206.

500 Karrie A Shogren, Michael L Wehmeyer, H Uyanik & M Heidrich, ‘Development of the Supported Decision making inventory system’, (2017), vol 55(6), *Intellectual and Developmental Disabilities*, pp 432-9; Karrie A Shogren, Graham G Rifenbark, Michael L Wehmeyer, Evan E Dean, Mary B Killeen & Judith Karsevar, ‘Refining the supported decision making inventory’, (2020), vol 17(3), *Journal of Policy and Practice in Intellectual Disabilities*, pp 195-206, 204.

501 Karrie A Shogren, Graham G Rifenbark, Michael L Wehmeyer, Evan E Dean, Mary B Killeen & Judith Karsevar, ‘Refining the supported decision making inventory’, (2020), vol 17(3), *Journal of Policy and Practice in Intellectual Disabilities*, pp 195-206.

502 Alberto Vasquez Encalada, Kimber Bialik & Kaitlin Stober, ‘Supported decision making in South America: Analysis of three countries’ experiences’, (2021), vol 18(10), *International Journal of Environmental Research and Public Health*, 5204 https://doi.org/10.3390/ijerph18105204

503 Alberto Vasquez Encalada, Kimber Bialik & Kaitlin Stober, ‘Supported decision making in South America: Analysis of three countries’ experiences’, (2021), vol 18(10), *International Journal of Environmental Research and Public Health*, 5204. https://doi.org/10.3390/ijerph18105204

504 Alberto Vasquez Encalada, Kimber Bialik & Kaitlin Stober, ‘Supported decision making in South America: Analysis of three countries’ experiences’, (2021), vol 18(10), *International Journal of Environmental Research and Public Health*, 5204. https://doi.org/10.3390/ijerph18105204

505 Deirdre O’Donnell, Éidín Ní Shé, Carmel Davies, Sarah Donnelly, Therese Cooney, Diarmuid O’Coimin, Diarmuid O’Shea, Lorraine Kyne, Diarmaid O’Sullivan, Bernadette Rock, Marie O’Shea, Eilish McAuliffe, Ann O’Shaughnessy & Thilo Kroll, ‘Promoting assisted decision-making in acute care settings for care planning purposes: Study protocol’, (2018), vol 1, *HRB Open Research*, 2 https://doi.org/10.12688/hrbopenres.12797.1

506 Christopher Schneiders, Elyn R Saks, Jonathan Martinis & Peter Blanck, ‘Psychiatric advance directives and supported decision-making: preliminary developments and pilot studies in California’ in Charlene Sunkel, Faraaz Mahomed, Michael Ashley Stein & Vikram Patel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 288-301.

507 Karrie Shogren, Michael Wehmeyer, Jonathan Martinis & Peter Blanck, ‘*Supported decision-making: Theory, research, and practice to enhance self-determination and Quality of life*, Cambridge University Press, pp 200-232.

508 Ariella Meltzer, Sally Robinson, Yvette Proud & Karen R Fisher, *Literature and practice review: support to make decisions that promote personal safety and prevent harm*, Social Policy Research Centre UNSW, 2016; Yvette Proud, *Standing strong in stormy weather: supporting decision making and problem solving using the ‘Tree of Life’ practice guide,* NSW Council of Social Service, 2018;Social Policy Research Centre, *Skilled to thrive: support to make decisions that promote personal safety and prevent harm*, Social Policy Research Centre UNSW, 2017.

509 Christine Bigby, Jacinta Douglas, Terry Carney, Shih-Ning Then, Ilan Wiesel & Elizabeth Smith, ‘Delivering decision making support to people with cognitive disability - what has been learned from pilot programs in Australia from 2010 to 2015’, (2017), vol 52(3), *Australian Journal of Social Issues*, pp 222-40.

510 Bizchut (The Israeli Human Rights Center for People with Disabilities), *Supported Decision-Making Service for Persons with Disabilities: Service Model*, Bizchut, 2016.

511 Lalcheva, Radoslava & Miryana Malamin, *Cost Benefit Analysis of Supported Decision-Making*, 2014.

512 Leimane-Veldmeijere, Ieva, Annija Mazapša, Aleksandra Pavlovska & Santa Skirmante, *Handbook: First Steps in Implementation of Supported Decision Making in Latvia*, Resource Centre for People with Mental Disability “ZELDA”, 2016.

513 Milena Johnová, Dana Kořínková & Jan Strnad, *Legal Cases of Legal Capacity Restoration and the Use of Support in Decision Making,* QUIP, 2017.

514 Elisabeth Pell & Virginia Mulkern, *Supported Decision-Making Pilot: Pilot Program Evaluation Year 2 Report*, Center for Public Representation and Nonotuck Resource Associates, Inc, 2016; Elizabeth Pell, *Supported Decison-Making New York: Evaluation Report of an Intentional Pilot*, Hunter College, CUNY, 2019.

515 The Arc of Northern Virginia (The Arc) & The Burton Blatt Institute at Syracuse University (BBI), *“I learned that I have a voice in my future”: Summary, Findings, and Recommendations of the Virginia Supported Decision-Making Pilot Project’*, http://www.supporteddecisionmaking.org/sdm-va-report-findings-2021

516 Elizabeth Pell, *Supported Decision-Making New York: Evaluation Report of an Intentional Pilot*, Hunter College, CUNY, 2019; Kristin Booth Glen, ‘Piloting personhood: reflections from the first year of a supported decision-making project’, (2017), vol 39, *Cardozo Law Review*, pp 495-520; Kristin Booth Glen, ‘Supported decision-making from theory to practice: further reflections on an intentional pilot project’, (2020), vol 13, *Albany Government Law Review*, pp 94-168.

517 Christine Bigby & Jacinta Douglas, ‘Examining complexities of support for decision making

practice’ in Ishita Khemka & Linda Hickson (eds), *Decision making by individuals with intellectual and developmental disabilities: integrating research into practice*, Springer, 2021, 65-94; Christine Bigby & Jacinta Douglas, ‘Supported decision making’, in Roger J Stancliffe, Michael L Wehmeyer, Karrie A Shogren & Brian H Abery (ed), *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan*, Springer International Publishing, 2020, pp 45-66;, Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences,’ (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481; Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘“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’, (2021), *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623; Ilan Wiesel, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, ‘The temporalities of supported decision-making by people with cognitive disability,’ (2020), *Social & Cultural Geography*, DOI: 10.1080/14649365.2020.1829689; Terry Carney, Shih-Ning Then, Christine Bigby, Ilan Wiesel, Jacinta Douglas & Elizabeth Smith, ‘Realising ‘Will, Preferences and Rights’: reconciling differences on best practice support for decision-making?’ (2019), vol 28(4), *Griffith Law Review*, pp 357-79; Shih-Ning Then, Terry Carney, Christine Bigby & Jacinta Douglas, ‘Supporting decision-making of adults with cognitive disabilities: the role of law reform agencies – recommendations, rationales and influence’ (2018) vol 61 *International Journal of Law and Psychiatry*, pp 64-75; Christine Bigby, Jacinta Douglas, Terry Carney, Shih-Ning Then, Ilan Wiesel & Elizabeth Smith, Delivering decision making support to people with cognitive disability - what has been learned from pilot programs in Australia from 2010 to 2015’, (2017), vol 52(3), *Australian Journal of Social Issues*, pp 222–40; Jacinta Douglas & Christine Bigby, ‘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’, (2020), vol 42(3), *Disability and Rehabilitation*, pp 434-41.

518 Jacinta Douglas, Christine Bigby & Elizabeth Smith, *Building capability to support client decision making: TAC Project No. T005*, Living with Disability Research Centre, La Trobe University, 2020.

519 Christine Bigby, Jacinta Douglas & Elizabeth Smith, *Considering human rights in decision making: Evaluation of the introduction of structured decision making framework in the Public Trustee Queensland, Living with Disability Research Centre*, La Trobe University, Bundoora, Vic, 2021.

520 Christiane Purcal, Trish Hill, Kelley Johnson & Rosemary Kayess, ‘Evaluation of the supported decision Making phase 2 (SDM2) project: Final report’ (Prepared for NSW Trustee and Guardian with the NSW Public Guardian, May 2017).

521 Office of the Public Advocate (Vic) & VALID, *Volunteer Programs of Support for Decision-Making: Lessons and Recommendations from the OVAL Project*, VALID and Office of the Public Advocate, 2017.

522 Office of the Public Advocate (Vic) & VALID, *Volunteer Programs of Support for Decision-Making: Lessons and Recommendations from the OVAL Project*, VALID and Office of the Public Advocate, 2017

523 Bizchut (The Israeli Human Rights Center for People with Disabilities), *Supported Decision-Making Service for Persons with Disabilities: Service Model* (Bizchut, 2016), 41, 56.

524 Eg, The Arc of Northern Virginia (The Arc) & The Burton Blatt Institute at Syracuse University (BBI), “*I learned that I have a voice in my future”: Summary, Findings, and Recommendations of the Virginia Supported Decision-Making Pilot Project’*, http://www.supporteddecisionmaking.org/sdm-va-report-findings-2021; Cf. Christine Bigby, Jacinta Douglas & Elizabeth Smith, *Considering human rights in decision making: Evaluation of the introduction of structured decision making framework in the Public Trustee Queensland*, Living with Disability Research Centre, La Trobe University, Bundoora, Vic, 2021.

525 Jacinta Douglas & Christine Bigby, ‘Development and preliminary evaluation of the decision support questionnaire’, ASID conference, 2021.

526 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘“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', (2021), *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623

527 Christine Bigby, Jacinta Douglas, Terry Carney, Shih-Ning Then, Ilan Wiesel & Elizabeth Smith, 'Delivering decision making support to people with cognitive disability - what has been learned from pilot programs in Australia from 2010 to 2015', (2017), vol 52(3), *Australian Journal of Social Issues*, pp 222–40.

528 Christine Bigby, Jacinta Douglas, Terry Carney, Shih-Ning Then, Ilan Wiesel & Elizabeth Smith, 'Delivering decision making support to people with cognitive disability - what has been learned from pilot programs in Australia from 2010 to 2015', (2017), vol 52(3), A*ustralian Journal of Social Issues*, pp 222–40.

529 Bizchut (The Israeli Human Rights Center for People with Disabilities), *Supported Decision-Making Service for Persons with Disabilities: Service Model* (Bizchut, 2016) 19.

530 Faraaz Mahomed, Michale Ashley Stein, Vikram Patel & Charlene Sunkel, 'Introduction - A "Paradigm Shift" in mental health care' in Faraaz Mahomed, Michale Ashley Stein, Vikram Patel & Charlene Sunkel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 1-16, 11.

531 Piers Gooding, *A new era for mental health law and policy: Supportive decision-making and the UN Convention on the Rights of Persons with Disabilities*, Cambridge University Press, 2017; Shirli Werner & Rachel Chabany, 'Guardianship law versus supported decision-making policies: perceptions of persons with intellectual or psychiatric disabilities and parents', (2016), vol 86(5), A*merican Journal of Orthopsychiatry*, pp 486-99; Nina A Kohn, Jeremy A Blumenthal & Amy T Campbell, 'Supported decision making: a viable alternative to guardianship? (Capacity, conflict and change: Elder law and estate planning themes in an aging world)', (2013), vol 117(4), *Penn State Law Review*, pp 1111-58; Eva Ryrstedt, 'Dementia and autonomy' in (ed) Ann Numhauser-Henning *Elder Law: Evolving European Perspectives*, Edward Elgar Publishing, 2017, pp 358-78; Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, '"A real bucket of worms": views of people living with dementia and family members on supported decision-making', (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587-608.

532 Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014), [22].

533 Nina A Kohn, Jeremy A Blumenthal & Amy T Campbell, 'Supported decision making: a viable alternative to guardianship? (Capacity, conflict and change: Elder law and estate planning themes in an aging world)', (2013), vol 117(4), *Penn State Law Review,* pp 1111-58, 1137.

534 Nina A Kohn & Jeremy A Blumenthal, 'A critical assessment of supported decision-making for persons aging with intellectual disabilities', (2014), vol 7(1, Supplement), *Disability and Health Journal*, S40-S41.

535 Matthé Scholten, Esther Braun, Jakov Gather & Jochen Vollmann, 'Combining supported decision-making with competence assessment: A way to protect persons with impaired decision-making capacity against undue influence', (2021), vol 21(11), *The American Journal of Bioethics*, pp 45-7.

536 Ann-Charlotte Nedlund & Annika Taghizadeh Larsson, 'To protect and to support: How citizenship and self-determination are legally constructed and managed in practice for people living with dementia in Sweden', (2016), vol 15(3), *Dementia*, 353.

537 Theresa Flavin, 'Supported decision making for people living with dementia', (2019), vol 19(1), *Dementia*, pp 95-97.

538 Terry Carney, 'Searching for workable alternatives to guardianship for vulnerable populations?', (2015), vol 1(1), *Ethics, Medicine and Public Health*, pp 113-19, 116.

539 Terry Carney, 'Searching for workable alternatives to guardianship for vulnerable populations?', (2015), vol 1(1), *Ethics, Medicine and Public Health*, pp 113-19, 116.

540 Terry Carney & Fleur Beaupert, 'Public and private bricolage: challenges balancing law, services and civil society in advancing the CRPD supported decision making', (2013), vol 36(1), *University of New South Wales Law Journal*, pp 175-201; Piers Gooding, *A new era for mental health law*

and policy: Supportive decision-making and the UN Convention on the Rights of Persons with Disabilities, Cambridge University Press, 2017, pp 244-6.

541 Terry Carney & Fleur Beaupert, ‘Public and private bricolage: challenges balancing law, services and civil society in advancing the CRPD supported decision making’, (2013), vol 36(1), *University of New South Wales Law Journal*, pp 175-201; see also Terry Carney, ‘Searching for workable alternatives to guardianship for vulnerable populations?’, (2015), vol 1(1), *Ethics, Medicine and Public Health*, pp 113-19.

542 Sheila M Wildeman, ‘Consent to psychiatric treatment: From insight (into illness) to incite (a riot)’ in (ed) Colleen Flood & Jennifer Chandler Law and mind: Mental health law and policy in Canada, LexisNexis, 2016.

543 Titti Mattsson & Lottie Giertz, ‘Vulnerability, law, and dementia: an interdisciplinary discussion of legislation and practice’, (2020), vol 21(1), *Theoretical Inquiries in law*, pp 139-59.

544 Lisa Brophy, Renata Kokanovic, Jacinthe Flore, Bernadette McSherry & Helen Herrman, ‘Community treatment orders and supported decision-making’, (2019), vol 10, *Frontiers in Psychiatry,* 414:1-12, 10.

545 Sheila M Wildeman, ‘Consent to psychiatric treatment: from insight (into illness) to incite (a riot)’ in (ed) Colleen Flood & Jennifer Chandler *Law and mind: Mental health law and policy in Canada*, LexisNexis, 2016; Terry Carney, ‘Supported decision-making for people with cognitive ipairments: an Australian perspective?’, (2015), vol 4, *Laws*, pp 37-59; Terry Carney & Shih-Ning Then, ‘Support for decision-making as people age with a cognitive impairment’ in (ed) Michelle Putnam & Christine Bigby *Handbook on Ageing with Disability,* Routledge, 2021, pp 186-95; Kevin T. Mintz & David C. Magnus, ‘Disability, , aging, and the importance of recognizing social supports in medical decision making’, (2021), vol 21(11), *The American Journal of Bioethics*, pp 1-3.

546 Kevin T Mintz & David C Magnus, ‘Disability, aging, and the importance of recognizing social supports in medical decision making’, (2021), vol 21(11), *The American Journal of Bioethics*, pp 1-3.

547 Joyce Simard & Ladislav Volicer, ‘Loneliness and isolation in long-term care and the COVID-19 pandemic’, (2020), vol 21(7), *Journal of the American Medical Directors Association*, pp 966-7.

548 Rachel Hale, Bernadette McSherry, Jeannie Marie Paterson, Lisa Brophy & Anna Arstein-Kerslake, *Consumer transactions: Equitable support models for individuals with decision-making impairments: A pilot study supported by the Melbourne Social Equity Institute and the Melbourne Law School Major Collaborative Fund Project*, (University of Melbourne, 2017); Canadian Centre for Elder Law, *Study Paper on Inclusive Investing: Respecting the Rights of Vulnerable Investors through Supported Decision-Making*, (2021).

549 Renata Kokanovic, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for supported decision-making to enhance the recovery of people experiencing severe mental health problems*, (Melbourne Social Equity Insitute, University of Melbourne, 2017).

550 Bernadette McSherry & Kay Wilson, ‘The concept of capacity in Australian mental health law reform: Going in the wrong direction?’, (2015), vol 40, *International journal of law and psychiatry*.

551 Jeanne Snelling & Alison Douglass, ‘Legal capacity and supported decision-making’ in (ed) Iris Reuvecamp & John Dawson *Mental capacity law in New Zealand*, Thomson Reuters, 2019, pp 163-77.

552 For a general discussion in the context of legal frameworks see Shih-Ning Then, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1), *Sydney Law Review*, 133-66

553 Peter Bartlett, ‘At the interface between paradigms: English mental capacity law and the CRPD’, (2020), vol 11, *Frontiers in psychiatry*, doi: 10.3389/fpsyt.2020.570735, p 10..

554 Antonio Martinez-Pujalte, ‘Legal capacity and supported decision-making: lessons from some recent legal reforms’, (2019), vol 8(4), *Laws*, doi:10.3390/laws8010004

555 Zachary Allen & Dari Pogach, ‘More states pass supported decision-making agreement’, (2019), vol 40 (1), *Bifocal: Journal of the ABA Commission on Law and Aging*, pp 159-61

556 Piers Gooding, *A new era for mental health law and policy: Supportive decision-making and the UN Convention on the Rights of Persons with Disabilities*, Cambridge University Press, 2017, p 224.

557 Kristin Booth Glen, ‘What judges need to know about supported decision-making, and why’, (2019), vol 58(1), *The Judges’ Journal,* pp 26-31, discussing the Texas law at 29.

558 Antonio Martinez-Pujalte, ‘Legal capacity and supported decision-making: lessons from some recent legal reforms’, (2019), vol 8(4), doi:10.3390/laws8010004

559 Antonio Martinez-Pujalte, ‘Legal capacity and supported decision-making: lessons from some recent legal reforms’, (2019), vol 8(4), *Laws*, doi:10.3390/laws8010004; Marie Fallon-Kund & Jerome E Bickenbach, ‘New legal capacity laws and the United Nations Convention on the Rights of Persons with Disabilities: an overview of five countries in Europe’, (2017), vol 24(3), *European Journal of Health Law*, pp 285-310.

560 Alberto Vasquez Encalada, K Bialik & K Stober, ‘Supported decision making in South America: analysis of three countries’ experiences’, (2021), vol 18(10), *International Journal of Environmental Research and Public Health*, 5204. https://doi.org/10.3390/ijerph18105204; Antonio Martinez-Pujalte, ‘Legal Capacity and Supported Decision-making: Lessons from some Recent Legal Reforms’, (2019), vol 8(4), doi:10.3390/laws8010004

561 Shih-Ning Then, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1), *Sydney Law Review*, pp 133-66; Canadian Centre for Elder Law, *Study Paper on Inclusive Investing: Respecting the Rights of Vulnerable Investors through Supported Decision-Making*, 2021.

562 In relation to healthcare, see Kevin De Sabbata & Elena Syurina, *Supported Decision-Making and Dementia*, Psychiatrie Verlag, 2019, p 19.

563 André Bzdera’, Supported Decision-Making Replaces Adult Guardianship in Austria (unpublished paper, 2019); cf Terry Carney, ‘Searching for workable alternatives to guardianship for vulnerable populations?’, (2015), vol 1(1), *Ethics, Medicine and Public Health*, pp 113-19. .

564 See, for example, Canadian Centre for Elder Law, *Study Paper on Inclusive Investing: Respecting the Rights of Vulnerable Investors through Supported Decision-Making*, 2021.

565 *Assisted Decision-Making (Capacity) Act 2015* (Ireland) s96.

566 Lise Barry & Susannah Sage-Jacobson, ‘Human rights, older people and decision making in Australia’, (2015), vol 9, *Elder Law Review,* pp 1-21.

567 Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A real bucket of worms”: views of people living with dementia and family members on supported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587-608.

568 *Quality of Care Principles 2014* (Cth) Part 5, Schedule 2 ‘Aged Care Quality Standards’, ‘Standard 1’; see Australian Government Aged Care Quality and Safety Commission, *Guidance and Resources for Providers to support the Aged Care Quality Standards,* Aged Care Quality and Safety Commission, March 2021, p 8. https://www.agedcarequality.gov.au/sites/default/files/media/Guidance_%26_Resource_V14.pdf

569 Sophie Nunnelley, *Personal support networks in practice and theory: Assessing the implications for supported decision-making law* Law Commission of Ontario, 2015 pp 36, 98-99; Kevin De Sabbata & Elena Syurina, *Supported Decision-Making and Dementia*, Psychiatrie Verlag, 2019, 25; Craig Sinclair, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A real bucket of worms”: views of people living with dementia and family members on supported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry,* pp 587-608; Kevin De Sabbata, ‘Dementia, treatment decisions, and the UN Convention on the Rights of Persons With Disabilities: a new framework for old problems’, (2020), vol 11, *Frontiers in Psychiatry*, doi: 10.3389/fpsyt.2020.571722

570 Terry Carney, ‘Supported decision-making for people with cognitive impairments: an Australian perspective?’, (2015), vol 4, *Laws*, pp 37-59, 41

571 Jacinta Douglas & Christine Bigby, ‘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’, (2020), vol 42(3), *Disability and Rehabilitation*, pp 434-41.

572 Jacinta Douglas & Christine Bigby, ‘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’, (2020), vol 42(3), *Disability and Rehabilitation*, pp 434-41, 439.

573 Christine Bigby, Jacinta Douglas & Elizabeth Smith, *Considering human rights in decision making: Evaluation of the introduction of structured decision making framework in the Public Trustee Queensland*, Living with Disability Research Centre, La Trobe University, Bundoora, Vic, 2021.

574 Christine Bigby, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘“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’, (2021), *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623

575 Goetz Ottmann, Keith McVilly & Margarita Maragoudaki, ‘’I walk from trouble’: exploring safeguards with adults with intellectual disabilities - an Australian qualitative study’, (2016), vol 31(1), *Disability & Society*, pp 47-63.

576 Goetz Ottmann, Keith McVilly & Margarita Maragoudaki, ‘’I walk from trouble’: exploring safeguards with adults with intellectual disabilities - an Australian qualitative study’, (2016), vol 31(1), *Disability & Society*, pp 47-63, 60.

577 Staci Converse, ‘Guardianship reform: supported decision-making and Maine’s new probate code’, (2018), vol 33(4), *Maine Bar Journal,* pp 25-8.

578 Lisa Brophy, Renata Kokanovic, Jacinthe Flore, Bernadette McSherry & Helen Herrman, ‘Community treatment orders and supported decision-making’, (2019), vol 10, *Frontiers in Psychiatry*, 414:1-12.

579 Sarah Buhagiar & Claire Azzopardi Lane, ‘Freedom from financial abuse: persons with intellectual disability discuss protective strategies aimed at empowerment and supported decision-making’, (2020), *Disability & Society*, pp 1-25.

580 Judy Allen & Tamara Tulich, ‘’I want to go home now’: restraint decisions for dementia patients in Western Australia’, (2015), vol 33(2), *Law in context*, 19.

581 Lucy Knox, Jacinta Douglas & Christine Bigby, ‘”I’ve never been a yes person”: decision-making participation and self-conceptualization after severe traumatic brain injury’, (2017), vol 39(22), *Disability and rehabilitation*, pp 2250-60; Christine Bigby & Jacinta Douglas, ‘Supported decision making’ in Roger J Stancliffe, Michael L Wehmeyer, Karrie A Shogren & Brian H Abery (ed) *Choice, preference, and disability: promoting self-determination across the lifespan*, Springer, 2020, pp 45-66; Anita Gjermestad, Laila Luteberget, Turid Midjo & Aud Elisabeth Witsø, ‘Everyday life of persons with intellectual disability living in residential settings: a systematic review of qualitative studies’, (2017), vol 32 (2), *Disability & Society*, 213-32; Deirdre Fetherstonhaugh, Laura Tarzia, Michael Bauer, Rhonda Nay & Elizabeth Beattie, ‘”The red dress or the blue?”: How do staff perceive that they support decision making for people with dementia living in residential aged care facilities?’ (2016), vol 35(2), *Journal of Applied Gerontology,* pp 209-26.

582 Jeremy Dixon, Sarah Donnelly, Jim Campbell & Judy Laing, ‘Safeguarding people living with dementia: how social workers can use supported decision-making strategies to support the human rights of individuals during adult safeguarding enquiries’, (2021), *The British Journal of Social Work*, pp 1-18.

583 Australian Law Reform Commission, *Elder Abuse – A National Legal Response*, Final Report (2017).

584 Karen Strickland, Kasia Bail, Sarah Cope, Murray Turner & Cameron Moss, ‘Supported decision-making to assist older persons experiencing elder abuse: An integrative review’, (2021), vol 28(4), *Collegian*, pp 447-55; see also Brian Roche, *Report: To investigate if supported decision making will reduce elder financial abuse in Australia*, Winston Churchill Memorial Trust, 2018. file:///C:/Users/julia/Downloads/projectReport-Roche_B_2017_Supported_decision_making_reduce_elder_financial_abuse_in_AUS%20(1).pdf

Bibliography

Articles, book chapters, books, reports

Abery, B H & R J Stancliffe, 'Ecology of self-determination' in D J Sands & M L Wehmeyer (ed), *Self-determination across the life span: Independence and choice for peole with disabilities*, Paul H Brookes Publishing, 1996, pp 111–46.

ACT Law Reform Advisory Council, 'Guardiansihp Report' <cdn.justice.act.gov.au/resources>

Alexandrov, N V & N Schuck, 'Coercive interventions under the new Dutch mental health law: Towards a CRPD-compliant law?', (2021), vol 76, *International Journal of Law and Psychiatry*, pp 101685–101685.

Allen, Judy & Tamara Tulich, ''I want to go home now': restraint decisions for dementia patients in Western Australia' (2015), vol 33(2), *Law in Context*, pp 1–23.

Allen, Zachary & Dari Pogach, 'More states pass supported decision-making agreement', (2019), vol 40(1), *Bifocal: Journal of the ABA Commission on Law and Aging*, pp 159–61.

Alston, Bruce, 'Towards supported decision-making: Article 12 of the Convention on the Rights of Persons with Disabilities and guardianship law reform' (2017), vol 35(2), *Law in Context* 21–39.

Appelbaum, Paul S & Manuel Trachsel, 'The Doctrine of Informed Consent Doesn't Need Modification for Supported Decision Making', (2021), 21(11), *The American Journal of Bioethics*, pp 27–9.

Araten-Bergman, Tal & Christine Bigby, 'Forming and supporting circles of support for people with intellectual disabilities – a comparative case analysis', (2021), *Journal of Intellectual & Developmental Disability* https://doi.org/10.3109/13668250.2021.1961049.

Arstein-Kerslake, Anna, 'An empowering dependency: exploring support for the exercise of legal capacity', (2016), vol 18(1) *Scandinavian Journal of Disability Research*, pp 77–92.

Arstein-Kerslake, Anna, 'Introduction to Criminal Responsibility' in Eilionoir Flynn, Anna Arstein-Kerlake, Cliona de Bhailis & Maria Laura Serra (ed) *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories*, Routledge, 2018, pp 19–21.

Australian Government Aged Care Quality and Safety Commission, *Guidance and Resources for Providers to support the Aged Care Quality Standards*, Aged Care Quality and Safety Commission, March 2021

Australian Government Department of Social Services, *Annual Report 2020–21*, Commonwealth of Australia, 2021.

Australian Institute of Health and Welfare, *Dementia in Australia: Web Report (Last updated 20 Sep 2021),* 2021.

Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report*, 2014.

Bailey, R, P Willner & S Dymond, 'A visual aid to decision-making for people with intellectual disabilities', (2011), vol 32(1), *Research in Developmental Disabilities*, pp 37–46.

Baldry, Eileen, Melissa Clarence, Leanne Dowse & Julian Trollor, 'Reducing vulnerability to harm in adults with cognitive disabilities in the Australian criminal justice system', (2013), vol 10(3), *Journal of Policy and Practice in Intellectual Disabilities*, pp 222–9.

Baldry, Eileen, Ruth McCausland, Leanne Dowse & Elizabeth McEntyre, *A Predictable and Preventable Path: Aboriginal People with Mental and Cognitive Disabilities in the Criminal Justice System*, University of New South Wales, 2015.

Barry, Lise & Susannah Sage-Jacobson, ‘Human rights, older people and decision making in Australia’, (2015), vol 9, *Elder Law Review*, pp 1–21

Bartlett, Peter, ‘At the interface between paradigms: English mental capacity law and the CRPD’, (2020), vol 11 *Frontiers in psychiatry,* doi: 10.3389/fpsyt.2020.570735

Batteux, Eleonore, Eamonn Ferguson & Richard J Tunney, ‘Do we make decisions for other people based on our predictions of their preferences? evidence from financial and medical scenarios involving risk’, (2020), vol 26(2) *Thinking & Reasoning,* pp 188–217

Beadle-Brown, Julie, ‘Supported decision-making in the United Kingdom:lLessons for future success’, (2015), vol 2(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 17–28

Beaupert, Fleur & L Steele, *Comments on Draft General Comment on Article 12 of the Convention. Submitted to the United Nations Committee on the Rights of Persons with Disabilities*, 2014.

Bedson, Lois, John Chesterman & Michael Woods, ‘The prevalence of elder abuse among adult guardianship clients’, (2018), vol 18, *MacQuarie Law Journal*, pp 15–53

Berggren, Ulrika Järkestig, ‘The Swedish Personal Ombudsman: support in decision-making and accessing human rights’ in Faraaz Mahomed, Michael Ashley Stein, Vikram Patel & Charlene Sunkel (ed) *Mental Health, Legal Capacity, and Human Rights* Cambridge University Press, 2021, pp 230–243

Bianchi, Daniel, ‘Advance directives: addressing the obligations of support as part of the right of a person with disabilities to equal recognition before the law?’ (2020), vol 70, *International Journal of Law and Psychiatry*, 101561

Bierer, Barbara E, Ari Ne’eman, Willyanne DeCormier Plosky, David H Strauss, Benjamin C Silverman & Michael Ashley Stein, ‘Integrating supported decision-making into the Clinical Research, (2021), vol 21(11), *The American Journal of Bioethics*, pp 32-35

Bigby, Christine, ‘Dedifferentiation and people with intellectual disabilities in the Australian National Disability Insurance Scheme: Bringing research, politics and policy together’, (2020), vol 45(4), *Journal of intellectual & Developmental Disability*, pp 309–19

Bigby, Christine, ‘Known well by no-one: trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community’, (2008), vol 33(2), *Journal of Intellectual & Developmental Disability*, pp 148–57

Bigby, Christine, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences’, (2021), *Journal of Intellectual and Developmental Disability*, DOI: 10.3109/13668250.2021.1954481

Bigby, Christine & Jacinta Douglas, ‘Supported decision making’ in Roger J Stancliffe, Michael L Wehmeyer, Karrie A Shogren & Brian H Abery (ed) *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan*, Springer International Publishing, 2020, pp 45–66

Bigby, Christine & Jacinta Douglas, ‘Examining complexities of support for decision making practice’ in Ishita Khemka and Linda Hickson (ed), *Decision making by pal disabilities: Integrating research into practice*, Springer, 2021.

Bigby, Christine, Jacinta Douglas, Terry Carney, Shih-Ning Then, Ilan Wiesel & Elizabeth Smith, ‘Delivering Decision Making Support to People with Cognitive Disability - What has been Learned from Pilot Programs in Australia from 2010 to 2015’, (2017), vol 52(3), *Australian Journal of Social Issues*, pp 222–40

Bigby, Christine, Jacinta Douglas & Lisa Hamilton, *Overview of Literature About Enabling Risk for People with Cognitive Disabilities in Context of Disability Support Services*, Living with Disability Research Centre, La Trobe University, 2018.

Bigby, Christine, Jacinta Douglas & Elizabeth Smith, *Considering Human Rights in Decision Making: Evaluation of the Introduction of Structured-Decision Making Framework in the Public Trustee Queensland*, Living with Disability Research Centre, La Trobe University, 2021.

Bigby, Christine Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then & Ilan Wiesel, ‘“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’, (2021), *Disability and Rehabilitation*, DOI: 10.1080/09638288.2021.1964623

Bigby, Christine, Marie Knox, Julie Beadle-Brown, Tim Clement, & Jim Mansell, ‘Uncovering dimensions of culture in underperforming group homes for people with severe intellectual disability’, (2012), vol 50(6), *Intellectual and developmental disabilities*, pp 452–67.

Bigby, Christine, Sophia Tipping, Emma Bould & Rebecca Thiele, *Final report: Strategies to Support People with Intellectual Disabilities to Participate in Voting*, Living with Disability Research Centre, La Trobe University, 2019.

Bigby, Christine, Ruth Webber & Barbara Bower, ‘Sibling roles in the lives of older group home residents with intellectual disability: working with staff to safeguard wellbeing’, (2015), vol 68, *Australian Social* Work’, pp 453–68

Bigby, Christine, Mary Whiteside & Jacinta Douglas, Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas, Living with Disability Research Centre, La Trobe University, 2015.

Bigby, Christine, Mary Whiteside & Jacinta Douglas, ‘Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services’, (2019), vol 44(4), *Journal of Intellectual & Developmental Disability*, pp 396–409

Bizchut (The Israeli Human Rights Center for People with Disabilities), *Supported Decision-Making Service for Persons with Disabilities: Service Model*, Bizchut, 2016.

Björnsdóttir, K G V Stefánsdóttir & A Stefánsdóttir, ‘‘It’s my life’: autonomy and people with intellectual disabilities’, (2015), vol 19(1), *Journal of Intellectual Disabilities*, pp 5–21

Blake, Meredith, Olivia Nicole Doray & Craig Sinclair, ‘Advance care planning for people with dementia in Western Australia: An examination of the fit between the law and practice’, (2018), vol 25(2), *Psychiatry, psychology, and law*, pp 197–218

Blake, Meredith, Cameron Stewart,, Pia Castelli-Arnold & Craiget Sinclair, ‘Supported decision-making for people living with dementia: an examination of four Australian guardianship laws’, (2021), vol 28(2), *Journal of Law and Medicine,* pp 389–420

Bohanna, India, Juliette Catherall & Kylie Dingwall, ‘Ensuring Indigenous Australians with acquired brain injuries have equitable access to the National Disability Insurance Scheme’, (2013), vol 37(6), *Australian and New Zealand Journal of Public Health*, pp 587–587

Bosco, Alessandro Justine Schneider, Donna Maria Coleston-Shields, Kaanthan Jawahar,Paul Higgs & Martin Orrell, ‘Agency in dementia care: systematic review and meta-ethnography’, (2019), vol 31(5), *International Psychogeriatrics*, pp 627–62

Boyle, Geraldine, ‘‘She’s usually quicker than the calculator’: financial management and decision-making in couples living with dementia’, (2013), vol 21(5), *Health & Social Care in the Community*, pp 554–62

Boyle, Geraldine, ‘Recognising the agency of people with dementia’, (2014), vol 29(7), *Disability & Society*, pp 1130–44

Brady, Anna M, Meghan M Burke, Trenton Landon & Kathleen Oertle, ‘Siblings of adults with intellectual and developmental disabilities: their knowledge and perspectives on guardianship and its alternatives’, (2019), vol 32(5), *Journal of Applied Research in Intellectual Disabilities*, pp 1078–87

Brophy, Lisa, Renata Kokanovic, Jacinthe Flore, Bernadette McSherry &, Helen Herrman, ‘Community treatment orders and supported decision-making’, (2019), vol 10, *Frontiers in Psychiatry*, 414:1–12

Brown, Bethany, ‘“For your own good:” Choice and the dangers of institutionalisation for older people’, (2018), vol 27(1), *Human Rights Defender* pp, 12–14

Browning, Michelle, Christine Bigby & Jacinta Douglas, ‘Supported decision making: understanding how its conceptual link to legal capacity isiInfluencing the development of practice’, (2014), vol 1(1,) *Research and Practice in Intellectual and Developmental Disabilities*, pp 34–45

Browning, Michelle, Christine Bigby & Jacinta Douglas, ‘A process of decision-making support: Exploring supported decision-making practice in Canada’, (2021), vol 46(2) *Journal of Intellectual & Developmental Disability*, pp 138–49

Browning, Michelle Jennett, ‘Developing an Understanding of Supported Decision-Making Practice in Canada: The Experiences of People with Intellectual Disabilities and Their Supporter’, PhD Thesis, La Trobe University, 2018

Bryant, Jamie, Marcus Sellars, Craig Sinclair, Karen Detering, , Kimberly Buck, Amy Waller, Ben White & Linda Nolte, ‘Inadequate completion of advance care directives by individuals with dementia: national audit of health and aged care facilities’, (2021), *BMJ Supportive & Palliative Care*, 0:1–10

Buhagiar, Sarah & Claire Azzopardi Lane, ‘Freedom from financial abuse: persons with intellectual disability discuss protective strategies aimed at empowerment and supported decision-making’, (2020), *Disability & Society*, pp 1–25

Bryne, Jennifer A, ‘Improving the peer review of narrative literature reviews’, (2016), *Research Integrity and Peer Review* DOI 10.1186/s41073-016-0019-2

Burgen, Brenda, ‘Reflections on the Victorian Office of the Public Advocate supported decision-making pilot project’, (2016), vol 3(2) *Research and practice in intellectual disabilities*, pp 165–81

Bzdera, André, ‘Supported decision-making replaces adult guardianship in Austria’ (Unpublished paper, 2019)

Callaghan, Sascha & Christopher James Ryan, ‘An evolving revolution: evaluating Australia’s compliance with the “Convention on the Rights of Persons with Disabilities” in mental health law’, (2016), vol 39(2), *University of New South Wales Law Journal*, pp 596–624

Callus, A M, ‘Removing obstacles to equal recognition for persons with intellectual disability: Taking exception to the way things are’, (2018), vol 12(3), *Alter*, pp 153–65

Campbell, S, K Stowe & E M Ozanne, ‘Interprofessional practice and decision support: An organizational framework applied to a mental health setting’ (2011) 25(6) *Journal of Interprofessional Care*, pp 423–7

Canadian Centre for Elder Law, *Study Paper on Inclusive Investing: Respecting the Rights of Vulnerable Investors through Supported Decision-Making* (2021)

Canadian Institute for Inclusion and Citizenship University of British Columbia, *Microboards, Social Capital and Quality of Life: Final Report of a Two Year Qualitative Inquiry*, Canadian Institute for Inclusion and Citizenship, University of British Columbia, 2020.

Carmody, John, Victoria Traynor & Anna Steele, ‘Dementia, decision aids and general practice’, (2015), vol 44(5), *Australian Family Physician*, pp 307–10

Carney, Terry, ’Adult guardianship and other financial planning mechanisms for people with cognitive impairment in Australia’ in L Ho & R Lee (eds), *Special Needs Financial Planning: A Comparative Perspective*, Cambridge University Press, 2019, pp. 3–29.

Carney, Terry, ‘Guardianship, Social Citizenship and Theorising Substitute Decision-Making Law’ in Israel Doron & Ann M Soden (ed), *Beyond elder law: New directions in law and aging,* Springer Berlin Heidelberg, 2012, pp 1 –17

Carney, Terry, ‘Participation and service access rights for people with intellectual disability: A role for law?’, (2013), vol 38(1) *Journal of Intellectual & Developmental Disability*, pp 59–69

Carney, Terry, ‘Searching for workable alternatives to guardianship for vulnerable populations?’, (2015), vol 1(1), *Ethics, Medicine and Public Health,* pp 113–19

Carney, Terry, ‘Supported decision-making for people with cognitive impairments: an Australian perspective?’, (2015), vol 4, *Laws*, pp 37–59

Carney, Terry, ‘Supporting people with cognitive disabilities with decision-making: any Australian law reform contributions?’, (2015), vol 2(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 6–16

Carney, Terry, ‘Prioritising supported decision-making: running on empty or a basis for glacial-to-steady progress?’, (2017), vol 6(4), *Laws*, pp 18–27

Carney, Terry, ‘Supported decision-making in Australia: meeting the challenge of moving from capacity to capacity-building?’ (2017), vol 35, *Law in Context*, pp 44–63

Carney, Terry, ‘Combating elder abuse: any role for supported-decision-making, adult guardianship or other laws?’ in Mala Kapur Shankardass (ed) *Combating Elder Abuse in Australia and India*, Nova Science, 2020, pp 265–87

Carney, Terry & Fleur Beaupert, ‘Public and private bricolage: challenges balancing law, services and civil society in advancing the CRPD supported decision making’ (2013), vol 36(1), *University of New South Wales Law Journal*, pp 175–201

Carney, Terry, Christine Bigby, Shih-Ning Then, Elizabeth Smith, Ilan Wiesel & Jacinta Douglas, ‘Paternalism to empowerment: all in the eye of the beholder?’, (2021), *Disability and Society*, DOI: 10.1080/09687599.2021.1941781

Carney, Terry & Shih-Ning Then, ‘Support for decision-making as people age with a cognitiveiImpairment’ in Michelle Putnam & Christine Bigby (ed), *Handbook on Ageing with Disability*, Routledge, 2021, pp 186–95

Carney, Terry, Shih-Ning Then, Christine Bigby, Ilan Wiesel & Jacinta Douglas, ‘National disability insurance scheme plan decision-making: or when tailormade case planning met taylorism & the algorithms?’, (2019), vol 42(3), *Melbourne University Law Review* pp 780–812

Carney, Terry, Shih-Ning Then, Christine Bigby, Ilan Wiesel, Jacinta Douglas & Elizabeth Smith, ‘Realising ‘Will, Preferences and Rights’: reconciling differences on best practice support for decision-making?’ (2019), vol 28(4), *Griffith Law Review*, pp 357–79

Caughey Gillian E, Catherine E Lang, Sarah C Bray, Max Moldovan, Robert N Jorissen, Steve Wesselingh & Maria C Inacio, ‘International and National Quality and Safety Indicators for Aged Care: Report for the Royal Commission into Aged Care Quality and Safety ‘, <https://agedcare.royalcommission.gov.au/sites/default/files/2020-08/research_paper_8_-_international_and_national_quality_and_safety_indicators_for_aged_care.pdf>

Caycho, Renato Antonio Constantino, ‘The Flag of Imagination: Peru’s New Reform on Legal Capacity for Persons with Intellectual and Psychosocial Disabilities and the need for understandings in Private Law’, (2020), vol 14(June) *The Age of Human Rights Journal,* pp 155–80.

Chesterman, John, ‘Modernising adult protection in an age of choice’, (2014), vol 73(4), *Australian Journal of Public Administration*, pp 517–24

Circles of Support and Microboards (COSAM), *Research and evaluation summary: academic research and professional evaluation of circles of support and microboards*, COSAM, nd. https://supporteddecisionmaking.com.au/wp-content/uploads/sites/4/2022/02/Research-and-Evaluation-Summary-Academic-Research-and-Professional-Evaluation-of-COSAM-Final.pdf

Clapton, Jayne, Lesley Chenoweth, Natalie Clements, Vicki Pascoe, Kylie Radal, Yvonne Cadet James, Val Wallace & Diane Cadet-James, *Impaired Decision-Making Capacity and Indigenous Queenslanders: Final Report for the Office of the Public Advocate, Queensland*, State of Qld, Department of Justice and Attorney-General, 2011

Cleary, M, T Raeburn, P Escott, S West & V Lopez, ‘”Walking the tightrope’: The role of peer support workers in facilitating consumers’ participation in decision-making’, (2018), vol 27(4), *International Journal of Mental Health Nursing*, pp 1266–72.

Collings, S, A Dew & L Dowse, ‘”They need to be able to have walked in our shoes”: What people with intellectual disability say about National Disability Insurance Scheme planning’, (2019), vol 44(1), *Journal of Intellectual & Developmental Disability,* pp 1–12.

Combrinck, Heléne & Enoch Chilemba, ‘‘The revolution will not be televised’: recent developments in mental health law reform in Zambia and Ghana’ in Faraaz Mahomed, Michale Ashley Stein, Vikram Patel & Charlene Sunkel ed) *Mental Health, Legal Capacity, and Human Rights*, Cambridge University Press, 2021, pp 184–98

Commissioner for Human Rights (Council of Europe), ‘Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities’, <https://rm.coe.int/16806da5c0>

Converse, Staci, ‘Guardianship Reform: Supported Decision-Making and Maine’s New Probate Code’, (2018), vol 33(4), *Maine Bar Journal*, pp 25–8.

Cooney, James, Michael Daly, Giles Newton-Howes, Kris Gledhill & Sarah Gordon, ‘Making the Convention on the Rights of Persons with Disabilities real: our word is our bond’ (2021), vol 134(1534), *The New Zealand Medical Journal (Online)*, pp 8–10

Corcoran, Joel D, Cindy Hamersma & Steven Manning, ‘The Clubhouse Model: A Framework for Naturally Occurring Supported Decision Making’ in Faraaz Mahomed, Michale Ashley Stein, Vikram Patel & Charlene Sunkel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 260-72.

Cukalevski, Emily, ‘Supporting choice and control—an analysis of the approach taken to legal capacity in Australia’s National Disability Insurance Scheme’, (2019), vol 8(2), *Laws*, pp 1–19

Curryer, Bernadette, Angela Dew, Roger J Stancliffe & Michele Y Wiese, ‘Adults with intellectual disability: choice and control in the context of family’ in Roger A Stancliffe et al (ed), *Choice, Preference and Disability: Promoting Self-Determination across the Lifespan*, Springer, 2020, pp 283–302

Curryer, Bernadette, Roger J Stancliffe & Angela Dew, ‘Self-determination: adults with intellectual disability and their family’, (2015), vol 40(4) *Journal of Intellectual & Developmental Disability*, pp 394–9

Curryer, Bernadette, Roger J Stancliffe, Michele Y Wiese & Angela Dew, ‘The experience of mothers supporting self-determination of adult sons and daughters with intellectual disability’, (2020), vol 33(3), *Journal of Applied Research in Intellectual Disabilities* 373–85

Daly, Rachel Louise, Frances Bunn & Claire Goodman, ‘Shared decision-making for people living with dementia in extended care settings: a systematic review’, (2018), vol 8(6), *BMJ Open* e018977-e018977

Davar, Bhargavi V, ‘Seher’s “Circle of Care” model in advancing supported decision making in India’ in Faraaz Mahomed, Michael Ashley Stein, Vikram Patel & Charlene Sunkel (ed), *Mental Health, Legal Capacity, and Human Rights* (2021), p 213–29

Davidson, Gavin, Lisa Brophy, Jim Campbell, Susan J Farrell, Piers Gooding & Ann-Marie O’Brien, ‘An international comparison of legal frameworks for supported and substitute decision-making in mental health services’, (2016), vol 44, *International Journal of Law and Psychiatry*, pp 30–40

Davidson, Gavin, Berni Kelly, Geraldine Macdonald, Maria Rizzo, Louise Lombard, Oluwaseye Abogunrin, Victoria Clift-Matthews & Alison Martin, ‘Supported decision making: a review of the international literature’, (2015), vol 38, *International Journal of Law and Psychiatry*, pp 61–7

Davidson, Hope, ‘The *Assisted Decision-Making (Capacity) Act 2015*: How will it change healthcare decision making for people with dementia’ (2016), vol 23(2) *Medico-Legal Journal of Ireland*, pp 62–9

Davies, Carmel, Francesco Fattori, O'Donnell Deirdre, Sarah Donnelly, Shé Éidín Ní, Marie O Shea, Lucia Prihodova, Caoimhe Gleeson, Áine Flynn, Bernadette Rock, Jacqueline Grogan, O'Brien Michelle, O'Hanlon Shane, Marie Therese Cooney, Marie Tighe & Thilo Kroll, 'What are the mechanisms that support healthcare professionals to adopt assisted decision-making practice? A rapid realist review', (2019), vol 19 *BMC Health Services Research*, pp 1–14

Davies, Rebecca Naomi, Shirli Werner & Amanda Sinai, 'Guardianship and Supported Decision-Making in Israel',(2017), vol 11(2), *Advances in Mental Health and Intellectual Disabilities*, pp 54–64

Dawson, John, 'A realistic approach to assessing mental health laws' compliance with the UNCRPD', (2015), vol 40 (2015/05/20) *International Journal of Law and Psychiatry*, pp 70–9

Dawson, John and George Szmukler, 'The 'Fusion Law' Proposals and the CRPD' in Faraaz Mahomed, Michael Ashley Stein, Vikram Patel & Charlene Sunkel (ed) *Mental health, legal capacity, and human rights* Cambridge University Press, 2021, pp 95–108

de Almeida, José Miguel Caldas, 'The CRPD Article 12, the Limits of Reductionist Approaches to Complex Issues and the Necessary Search for Compromise', (2019), vol 18(1), *World Psychiatry*, pp 46–7

De Sabbata, Kevin, 'Dementia, Treatment Decisions, and the UN Convention on the Rights of Persons With Disabilities: A New Framework for Old Problems' (2020) 11 *Frontiers in Psychiatry*, doi: 10.3389/fpsyt.2020.571722

De Sabbata, Kevin & Elena Syurina, *Supported Decision-Making and Dementia*, Psychiatrie Verlag, 2019

de Sande, C A, B F Ros, J M S i Chavero, J M S, L Marroyo, P Leotti, S Karagouni, K Hänninen & J Churchill, (I-DECIDE Partnership), 'From "guardians" to "supporters": supported Decision-making in service provision for persons with disabilities', 2018

Deci, E L & R M Ryan, 'Self-determination theory' in J D Wright (ed) *International Encyclopedia of the Social and Behavioral Sciences*, Elsevier Ltd, 2015, pp 486–91

Del Villar, Katrine, 'Should supported decision-making replace substituted decision-making? The Convention on the Rights of Persons with Disabilities and Coercive Treatment under Queensland's Mentl Health Act 2000', (2015), vol 4(2), *Laws*, pp 173–200

Devi, Nandini, 'Supported decision-making and personal autonomy for persons with intellectual isabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities', (2013), vol 41(4), *The Journal of Law, Medicine & Ethics*, pp 792–806

Devi, Nandini, Birgit Prodinger, Andrew Pennycott, Roja Sooben & Jerome Bickenbach 'Investigating supported decision-making for persons with mild to moderate intellectual disability using institutional ethnography', (2020), vol 17(2), *Journal of Policy and Practice in Intellectual Disabilities*, pp 143–56

Dew, Angela and Leanne Dowse, *The relational nature of planning with people with intellectual disability and complex support needs* (Australasian Society for the Study of Intellectual Disability, 2018), vol 39, pp 20–4

Dhanda, Amita and Gabor Gombos, 'Questions of Criminal Culpability and Persons with Disabilities' in Eilionoir Flynn, Anna Arstein-Kerlake, Cliona de Bhailis & Maria Laura Serra, (ed), *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories*, Routledge, 2018, pp 32–42

Diller, Rebekah, 'Legal capacity for all: including older persons in the shift from adult guardianship to supported decision-making', (2016), vol 43, *Fordham Urban Law Journal*, pp 495–538

Disability Voices United, *With Support and without the Court: Supported Decision-Making Handbook for Parents of Adults with Developmental Disabilities in California* (2020) SDM-Handbook_Oct2020.6.pdf (disabilityvoicesunited.org)

Dixon, Jeremy, Sarah Donnelly, Jim Campbell & Judy Laing 'Safeguarding people living with dementia: how social workers can use supported decision-making strategies to support the human rights of individuals during adult safeguarding enquiries', 00, (2021) ,*The British Journal of Social Work*, pp 1–18

Donnelly, Mary, 'Deciding in dementia: the possibilities and limits of supported decision-making', (2019), vol 66, *International Journal of Law and Psychiatry*, 101466: 1–7.

Donnelly, Sarah, Diarmuid Ó Coimín, Deidre O'Donnell, Éidín Ní Shé, Carmel Davies, Lauren Christophers, Steve Mc Donald & Thilo Kroll,'Assisted decision-making and interprofessional collaboration in the care of older people: a qualitative study exploring perceptions of barriers and facilitators in the acute hospital setting', (2021), *Journal of Interprofessional Care*, pp 1–11.

Douglas, Jacinta & Christine Bigby, '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' (2020), vol 42(3), *Disability and Rehabilitation*, pp 434–41

Douglas, Jacinta & Christine Bigby, 'Development and preliminary evaluation of the decision support questionnaire' (12th and 17th November, 2021).

Douglas, Jacinta, Christine Bigby, Lucy Knox & Michelle Browning 'Factors that underpin the delivery of effective decision-making support for people with cognitive disability', (2015), vol 2(1), *Research and Practice in Intellectual and Developmental Disabilities* 37.

Douglas, Jacinta, Christine Bigby & Elizabeth Smith, *Building capability to support client decision making: TAC Project No.T005,* Living with Disability Research Centre, La Trobe University, 2020.

Duffield L, S Koritsas S, J Watson & N Hagiliassis, 'Decision-making support for people with cognitive disability. A guide for disability workers', Melbourne Scope (Aust), 2016

Duffy, Richard M. and Brendan D. Kelly, 'India's Mental Healthcare Act, 2017: content, context, controversy', (2019), vol 62, *International Journal of Law and Psychiatry*, pp 169–78

Edwards, Niki, Julie King, Sara Hair & Kate Walton, *Articulation of a Best Practice Model of Guardianship Advocacy Services: For Older People and People with Cognitive Disability at risk of Abuse and Neglect* (Technical Report, 2019)

Elster, N & K Parsi, 'Transitioning from adolescence to adulthood with autism spectrum disorder: an overview of planning and legal issues', (2020), vol 43(4) *Psychiatric Clinics of North America*, pp 723–733

Elwyn, Glyn, Dominick Frosch, Richard Thomson, Natalie Joseph-Williams, Amy Lloyd, Paul Kinnersley, Emma Cording, Dave Tomson, Carole Dodd, Stephen Rollnick, Adrian Edwards & Michael Barry, 'Shared decision making: a model for clinical practice', (2012), vol 27(10), *Journal of General Internal Medicine: JGIM* pp, 1361–67

Encalada, Alberto Vasquez, K Bialik & K Stober, 'Supported decision making in South America: analysis of three countries' experiences', (2021), vol 18(10), *International Journal of Environmental Research and Public Health*, 5204. https://doi.org/10.3390/ijerph18105204

European Institute of National Human Rights Institutions (ENNHRI) and Mental Health Europe, ’Implementing supported decision-making, developments across Europe and the role of national human rights institutions’(8 June 2020). /ennhri.org/news-and-blog/implementing-supported-decision-making-for-people-with-disabilities-new-report-shows-developments-in-europe-and-the-role-of-nhris/?msclkid=86e07153cf3911eca8d523f661e4cd34

European Union Agency for Fundamental Rights, *Choice and control: The right to independent living: Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States* (2012) https://fra.europa.eu/en/publication/2012/choice-and-control-right-independent-living

Fallon-Kund, Marie & Jerome E Bickenbach, ‘New legal capacity laws and the United Nations Convention on the Rights of Persons with Disabilities: an overview of five countries in Europe’, (2017), vol 24(3), *European Journal of Health Law*, pp 285–310

Ferm, Ulrika, Steven J Bloch & Charlotta Saldert, ‘Negotiating disagreement in picture symbol supported decision making’, (2016), vol 6(2), *Journal of Interactional Research in Communication Disorders*, pp 131–56

Fetherstonhaugh, Deirdre, Linda McAuliffe, Christopher Shanley, Michael Bauer & Elizabeth Beattie , ’“Did I make the right decision?”: The difficult and unpredictable journey of being a surrogate decision maker for a person living with dementia’ (2019), vol 18(5), *Dementia (London, England)*, pp 1601–14

Fetherstonhaugh, Deirdre, Jo-Anne Rayner & Laura Tarzia, ‘Hanging on to some autonomy in decision-making: How do spouse carers support this?’ (2019), vol 18(4), *Dementia: The International Journal of Social Research and Practice*, pp 1219–36

Fetherstonhaugh, Deirdre, Laura Tarzia, Michael Bauer, Rhonda Nay & Elizabeth Beattie,’”The red dress or the blue?”: How do staff perceive that they support decision making forpPeople with dementia living in residential aged care facilities?’, (2016), vol 35(2), *Journal of Applied Gerontology*, pp 209–26

Fetherstonhaugh, Deirdre, Laura Tarzia & Rhonda Nay, ‘Being central to decision making means I am still here!: The essence of decision making for people with dementia’ (2012), vol 27(2), *Journal of Aging Studies* pp 143–50.

Francis, Leslie P, ‘Supported decisions as the patient’s own?’, (2021), vol 11, *The American Journal of Bioethics*, pp 24–6

Freeman, Melvyn Colin, Kavitha Kolappa, Jose Miguel Caldas de Almeida, Arthur Kleinman, Nino Makhashvili, Sifiso Phakathi, Benedetto Saraceno & Graham Thornicroft,’Reversing hard won victories in the name of human rights: A critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities’, (2015), vol 2(9),*The Lancet Psychiatry*, pp 844–9

Frohmader, Carolyn & Therese Sands, *Australian Cross Disability Alliance (ACDA) Submission to the Senate Inquiry into Violence, abuse and neglect against people with disability in institutional and residential settings’,* Australian Cross Disability Alliance (ACDA), 2015

Fulton, Kate & Leanne Pearman, *Supported Decision Making*, Western Australia’s Individualised Services, undated.

Funk, Michelle, Natalie Drew Bold, Joana Ansong, Daniel Chisholm, Melita Murko, Joyce Nato, Sally-Ann Ohene, Jasmine Vergara & Edwina Zoghbi, ‘Strategies to achieve a rights-based approach through WHO QualityRights’ in Faraaz Mahomed, Michale Ashley Stein, Vikram Patel & Charlene Sunkel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 244–59

Galderisi, Silvana, ‘The UN Convention on the Rights of Persons with Disabilities: great opportunities and dangerous interpretations’, (2019), vol 18(1) *World Psychiatry*, pp 47–8

Giertz, Lottie, Ulla Melin Emilsson & Emme-Li Vingare, ‘Family caregivers and decision-making for older people with dementia’, (2019), vol 41(3), *The Journal of Social Welfare & Family law*, pp 321–38

Gill, N S, John A Allan, Belinda Clark & Alan Rosen, ‘Human rights implications of introducing a new mental health act – principles, challenges and opportunities’, (2020), vol 28(2), *Australasian Psychiatry,* pp 167–70

Gjermestad, Anita, Laila Luteberget, Turid Midjo & Aud Elisabeth Witsø ‘Everyday life of persons with intellectual disability living in residential settings: a systematic review of qualitative studies’, (2017), vol 32(2,) *Disability & Society,* pp 213–32

Glen, Kristin Booth, ‘The perils of guardianship and the promise of supported decision making’, (2014), vol 48(1–2), *Clearinghouse Review*, pp 17–22

Glen, Kristin Booth, ‘Piloting personhood: reflections from the first year of a supported decision-making project’, (2017), vol 39, *Cardozo Law Review*, pp 495–520

Glen, Kristin Booth, ‘Introducing a new human right: learning from others, bringing legal capacity home’, (2018) vol 49(3), *Columbia Human Rights Law Review* 1–96

Glen, Kristin Booth, ‘What Judges need to know about supported decision-making, and why’, (2019), vol 58(1), *The Judges’ Journal*, pp 26–31

Glen, Kristin Booth, ‘Supported decision-making from theory to practice: further reflections on an intentional pilot Project’, (2020), vol 13, *Albany Government Law Review*, pp 94–168

Gooding, Piers, ‘Supported decision-making: a rights-based disability concept and its implications for mental health law’, (2013), vol 20(3), *Psychiatry, Psychology and Law*, pp 431–51

Gooding, Piers, *A New Era for Mental Health Law and Policy: Supportive Decision-making and the UN Convention on the Rights of Persons with Disabilities*, Cambridge University Press, 2017.

Gooding, Piers, ‘Mind the gap: researching ‘Alternatives to coercion’ in mental health care’ in Faraaz Mahomed, Michael Ashley Stein, Vikram Patel & Charlene Sunkel (ed) *Mental health, legal capacity, and human rights* Cambridge University Press, 2021, pp 273–287

Gooding, Piers & Terry Carney, ‘Australia: lessons from a reformist path to supported decision-making’ (forthcoming)

Gooding, Piers & Elionoir Flynn, ‘Querying the call toiIntroduce mental capacity testing to rights-based mental health law’, (2015), vol 4(2), *Laws*, pp 245–7

Gooding, Piers, Bernadette McSherry & Anna Arstein-Kerslake, ‘Supported decision-making in criminal proceedings: a sociolegal empirical study’, (2021), vol 1–11, *Journal of Disability Policy Studies*, p p.104420732110263

Gordon, Tess, Angela Dew & Leanne Dowse, ‘Listen, learn, build, deliver? Aboriginal and Torres Strait Islander policy in the National Disability Insurance Scheme’, (2019), vol 54(3), *Australian Journal of Social Issues*, pp 224–44

Haberstroh, F & Oswald J Pantel, ‘Ensure Project: supported decision-naking and capacity assessment in clinical Dementia Research’, (2017), vol 1(S1), *Innovation in Aging*, pp 729.

Haberstroh, Julia, Susanne Penger, Anne Messemaker & Maren Knebel, ‘Observational assessment of communication to empower patients with dementia to make legally effective decisions – revalidation of CODEM(amb)’ (2021) (2021/07/29) *Aging & Mental Health* 1–8, DOI: 10.1080/13607863.2021.1952549

Hale, Rachel, Bernadette McSherry, Jeannie Marie Paterson, Lisa Brophy & Anna Arstein-Kerslake, *Consumer Transactions: Equitable Support Models for Individuals with Decision-making Impairments: A pilot study supported by the Melbourne Social Equity Institute and the Melbourne Law School Major Collaborative Fund Project,* University of Melbourne, 2017.

Hamilton, Sarah, Paulina Szymczynska, Naomi Clewett, Jill Manthorpe, Jerry Tew, John Larsen & Vanessa Pinfold, ‘The role of family carers in the use of personal budgets by people with mental health problems’, (2017), vol 25(1), *Health & Social Care in the Community*, pp 158–66

Harding, Rosie, ‘Legal constructions of dementia: discourses of autonomy at the margins of capacity’, (2012), vol 34(4), *The Journal of Social Welfare & Family Law* 425–42

Harding, Rosie, ‘Care and relationality: supported decision-making under the UN CRPD’ in Harding R, R Fletcher & C Beasley (ed), *Revaluing Care in Theory, Law and Policy: Cycles and Connections*, Routledge, 2017.

Harding, Rosie & Taşcıoğlu Ezgi, ‘Supported Decision-Making from Theory to Practice: Implementing the Right to Enjoy Legal Capacity’, (2018), vol 8(2), *Societies (Basel, Switzerland)*, 25 doi:10.3390/soc8020025

Harding, Rosie & Ezgi Taşcioğlu, ‘’That’s a bit of a minefield’: Supported decision making in intellectually disabled people’s intimate lives’ in C Ashford & A Maine (ed) *Research Handbook on Gender, Sexuality and Law,* Edward Elgar, 2020, pp 256–70

Harding, Rosie, Ezgi Taşcioğlu & Magdalena Furgalska, *Supported Will Making: A Socio-Legal Study of Experiences, Values, and Potential in Supporting Testamentary Capacity.* Birmingham Law School, University of Birmingham, 2019

Harris, Jasmine E, ‘The role of support in sexual decision-making for people with intellectual and developmental disabilities’, (2016), vol 77, *Ohio State Law Journal Furthermore*, pp 83–104

Heid, Allison R, Lauren R Bangerter, Katherine Abbott & Kimberly Van Haitsma, ‘Do family proxies get it right? Concordance in reports of nursing home residents’ everyday preferences’, (2017), vol 36(6), *Journal of Applied Gerontology*, pp 667–91

Higgins, Kate & Cassy Nunan, ‘Choice and control: Why peer education is vital in supporting people with a lived experience of mental illness to exercise choice and control under the NDIS’, (2014), vol 27(5), *Parity* 52–3

Holler, Roni, Shirli Werner, Yotab Tolum & Miriam Pomerantz ‘Choice within the Israeli welfare state: lessons learned from legal capacity housing services’ in Roger J Stancliffe, Roger J Stancliffe, Michael L Wehmeyer, Karrie A Shogren & Brian H Abery (ed), *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan*, Springer, 2020

Holness, W, ‘Equal recognition and legal capacity for persons with disabilities: Incorporating the principle of proportionality’, (2014), vol 30, *South African Journal on Human Rights*, pp 313–44

Human Rights Council, *Report of the Special Rapporteur on the rights of persons with disabilities*, 37th sess, Agenda Item 3, UN Doc A/HRC/37/56 (12 December,2017)

IHC New Zealand, ‘Research report: What does helpful supported decision-making look like to people with intellectual disabilities? https://ihc.org.nz/sites/default/files/IHC%20A4%20Booklet%20Web.pdf

IHC New Zealand, ‘Supporting Decision-Making. A Guide for Supporters of people with Intellectual Disability’ (20xx) https://ihc.org.nz/sites/default/files/documents/10007_1511_SupportedDecisionMaking_Resource_V4.3_WEB_0.pdfInamdar, Mukul, Michael Ashley Stein and Joske Bunders, ‘Does “supported decision-making” in India’s Mental Health Care Bill, 2013, measure up to the CRPD’s standards?’ (2016), vol 1, *Indian Journal of Medical Ethics* pp, 229–36

Jamieson, R, K Theodore & R Raczka, ‘Becoming a mother: Supported decision-making in context’, (2016), vol 20(4), *Journal of Intellectual Disabilities*, pp 313–28

Jaworska, Agnieszka & Winston Chiong, ‘Supported decision-making for people with dementia should focus on heir values’, (2021), vol 21(11), *The American Journal of* Bioethic, pp 19–21

Jayes, M, L Austin & L J E Brown, ‘Supported decision-making and mental capacity assessment in care homes: A qualitative study’, (2020), *Health & Social Care in the Community* 00:1–9.

Jeste, Dilip V, Graham M L Eglit, Barton W Palmer, Jonathan G Martinis, Peter Blanck & Elyn R Saks, ‘Supported decision making in serious mental illlness’, (2018), vol 81(1), *Psychiatry*, pp 28–40

Jesus, Tiago, Christina Papadimitriou, Felicity Bright, Nicola Kayes & Cheryl Cott, ‘What person-centered rehabilitation means in concept and practice: the person-centered rehabilitation model for adult physical rehabilitation derived from a scoping review and thematic Ssnthesis’, (2021), vol 102(10), *Archives of Physical Medicine and Rehabilitation*, pp e116-e116

Johnová, Milena, Dana Kořínková & Jan Strnad, *Legal Cases of Legal Capacity Restoration and the Use of Support in Decision Making*, QUIP, 2017.

Kanter, Arlene S & Yotam Tolub, ‘The fight for personhood, legal capacity, and equal recognition under the law for people with disabilities in Israel and beyond’, (2017), vol 39(2), *Cardozo Law Review*, pp 557–610.

Keeling, Amanda, ‘Supported decision making: the rights of people with dementia’, (2016), vol 30(30), *Nursing Standard*, pp 38–44

Keyes, Sarah E, Charlotte L Clarke & Catherine E Gibb, ‘Living with dementia, interdependence and citizenship: Narratives of everyday decision-making’, (2019), vol 34(2), *Disability & Society*, pp 296–319

Kim, Scott Y H, Jason H Karlawish, H Myra Kim, Ian F Wall, Andrea C Bozoki & Paul S Appelbaum, ‘Preservation of the capacity to appoint a proxy decision maker: implications for dementia research’, (2011), vol 68(2), *Archives of General Psychiatry*, pp 214–20

Knauer, Nancy J, ‘LGBT issues and adult guardianship: a comparative perspective’, in Kim Dayton (ed) *Comparative perspectives in guardianship,* University of Carolina Press, 2013.

Knight, Fauzia, Renata Kokanovic, Damien Ridge, Lisa Brophy, Nicholas Hill, Kate Johnston-Ataata & Helen Herrman, ‘Supported decision-making: the expectations held by people with experience of mental illness’, (2018), vol 28(6), *Qualitative Health Research*, pp 1002–15

Knox, Lucy, Jacinta M Douglas & C Bigby, ‘Becoming a decision-making supporter for someone with acquired cognitive disability following traumatic brain injury’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 12–21

Knox, Lucy, Jacinta M Douglas & Christine Bigby, '"I won't be around forever": understanding the decision-making experiences of adults with severe TBI and their parents' (2016), vol 26(2), *Neuropsychological Rehabilitation*, pp 236–60

Knox, Lucy, Jacinta M Douglas & Christine Bigby, '"I've never been a yes person": decision-making participation and self-conceptualization after severe traumatic brain injury', (2017), vol 39(22), *Disability and Rehabilitation*, pp 2250–60

Knox, Lucy, Jacinta M Douglas & Christine Bigby, 'Whose decision is it anyway? How clinicians support decision-making participation after acquired brain injury', (2013), 35(22), *Disability and Rehabilitation*, pp 1926–32

Knox, Lucy, Jacinta M Douglas & Christine Bigby, ''The biggest thing is trying to live for two people': spousal experiences of supporting decision-making participation for partners with TBI', (2015), vol 29(6), *Brain Injury*, pp 745–57

Kohn, Nina A, 'Legislating supported decision-making', (2021), vol 58(2), *Harvard Journal on Legislation*, pp 313–56

Kohn, Nina A & Jeremy A Blumenthal, 'A critical assessment of supported decision-making for persons aging with intellectual disabilities', (2014), vol 7(1, Supplement), *Disability and Health Journal*, S40–S43

Kohn, Nina A, Jeremy A Blumenthal & Amy T Campbell, 'Supported decision making: A viable alternative to guardianship?, (2013), vol 117(4), *Penn State Law Review*, pp 1111–58

Kohn, Nina A, 'Realizing supported decision-making: What it does—and does not—require', (2021), vol 21(11), *The American Journal of Bioethics*, pp 313–56

Kokanovic, Renata, Lisa Brophy, Bernadette McSherry, Jacinthe Flore, Kristen Moeller-Sazone & Helen Herrman, 'Supported decision-making from the perspectives of mental health service users, family members supporting them and mental health practitioners', (2018), vol 52(9), *Australian and New Zealand Journal of Psychiatry*, pp 826–33

Kokanovic, Renata, Lisa Brophy, Berndatte McSherry, Nicholas Hill, Kate Johnston-Ataata, Kristen Moeller-Saxone & Helen Herrman, *Options for Supported Decision-Making to Enhance the Recovery of People Experiencing Severe Mental Health Problems*, Melbourne Social Equity Institue, University of Melbourne, 2017.

Kong, Camillia, 'The Convention for the Rights of Persons with Disabilities and article 12: prospective feminist lessons against the "will and preferences" paradigm', (2015), vol 4(4), *Laws*, pp 709–28

Kong, Camillia, Efrem Mehret & Megan Campbell, 'Education versus screening: the use of capacity to consent tools in psychiatric genomics', (2020), vol 46(2), *Journal of Medical Ethics*, pp 137–42

Kripke, Clarissa, 'Adults with Developmental Disabilities: a comprehensive Approach to Medical Care', (2018), vol 97(10), *American Family Physician*, pp 649–56

Lalcheva, Radoslava & Miryana Malamin, *Cost Benefit Analysis of Supported Decision-Making*, 2014.

Laragy, Carmel & Karen Raewen Fisher, 'Choice, control and individualfFunding: the Australian National Disability Insurance Scheme' in Roger J Stancliffe, Michael L Wehmeyer, Karrie A Shogren & Brian H Abery (ed), *Choice, Preference, and Disability: Promoting Self-Determination Across the Lifespan*, Springer International Publishing, 2020, pp 133–54

Leimane-Veldmeijere, Ieva, Annija Mazapša, Aleksandra Pavlovska & Santa Skirmante, *Handbook: First Steps in Implementation of Supported Decision Making in Latvia*, Resource Centre for People with Mental Disability “ZELDA”, 2016

Lipp, Volker & Julian O Winn, ‘Guardianship and autonomy: foes or friends?’, (2011), vol 5, *Journal of International Aging, Law & Policy*, pp 41–56

Lisa, Brophy, McSherry Bernadette, Renata Kokanovic, Kristen Moeller-Saxone & Helen Herrman*, Guidelines for supported decision-making in mental health services*, University of Melbourne, 2017

Lloyd, Jan, Karen Moni, Monica Cuskelly & Anne Jobling, ‘Exploring the complexity of implementing National Disability Insurance Scheme plans for adults with intellectual disability: parents’ perspectives’, (2021), *Journal of Intellectual & Developmental Disability*, pp 281–90

Lühnen, Julia, Burkhard Haastert, Ingrid Mühlhauser & Tanja Richter, ‘Informed decision-making with and for people with dementia – efficacy of the PRODECIDE education program for legal representatives: protocol of a randomized controlled trial (PRODECIDE-RCT)’ (2017), vol 17(1), *BMC Geriatrics*, 217: 1–11

Lyle O’Brien, Connie & John O’Brien, ‘The Origins of person-centred planning: A community of practice perspective’ in John O’Brien & Connie Lyle O’Brien (ed) *Implementing person-centered planning: volume II*, Inclusion Press, 2002.

Mahomed, Faraaz, Michael Ashley Stein, Vikram Patel & Charlene Sunkel, ‘Introduction – A “paradigm shift” in mental health care’ in Faraaz Mahomed, Michael Ashley Stein, Vikram Patel & Charlene Sunkel (ed), *Mental health, legal capacity, and human rights,* Cambridge University Press, 2021, pp 1–16

Maker, Yvette, Anna Arstein-Kerslake, Bernadette McSherry, Jannie Marie Paterson & Lisa Brophy, ‘Ensuring equality for persons with cognitive disabilities in consumer contracting: An international human rights law perspective’ (2018), vol 19(1,) *Melbourne Journal of International Law,* pp 178–99

Martin, Wayne & Sándor Gurbai, ‘Surveying the Geneva impasse:coercive care and human rights’, (2019), vol 64, *International Journal of Law and Psychiatry*, pp 117–28

Martin, Wayne, Sabine Michalowski, Jill Stavert, Adrian Ward, A Ruck Keene, Colin Caughey, Alision Hempsey & Rebecca McGregor, *Three Jurisdictions Report: Towards compliance with CRPD Article 12 in Capacity/Incapacity Legislation across the UK* , Essex Autonomy Project, 2016.

Martiniez-Pujalte, Antonio, ‘Legal capacity and supported decision-making: lessons from some recent legal reforms’, (2019), vol 8(4), *Laws*, doi:10.3390/laws8010004

Martinis, J, Jason Harris, Dean Fox & Peter Blanck, ‘State guardianship laws and supported decision-making in the United States after Ross and Ross v. Hatch: analysis and implications for research, policy, education, and advocacy’, (2021), *Journal of Disability Policy Studies*, doi: 10.1177/10442073211028586

Mattsson, Titti & Lottie Giertz, ‘Vulnerability,lLaw, and dementia: an interdisciplinary discussion of legislation and practice’, (2020), vol 21(1), *Theoretical Inquiries in Law*, pp 139–159

Maylea, Chris, Ann Jorgensen, Sarah Matta, Katherine Ogilvie & Paul Wallin, ‘Consumers’ experiences of mental health advance statements’, (2018), vol 7(22), *Laws*, doi:10.3390/laws7020022

Maylea, Christopher H, ‘A rejection of involuntary treatment in mental health social work’, (2017), vol 11(4), *Ethics & Social Welfare*, pp 336–352

McCarron, M, P McCallion, E Reilly & N Mulryan, ‘A prospective 14-year longitudinal follow-up of dementia in persons with Down syndrome: Dementia follow-up’, (2014), vol 58(1), *Journal of Intellectual Disability Research*, pp 61–70

McCarthy, Michelle, Claire Bates, Nicola Elson, Siobhan Hunt, Karen Milne-Skillman & Rachel Forrester–Jones, ‘‘Love makes me feel good inside and my heart is fixed’: What adults with intellectual disabilities have to say about love and relationships’, (2021) *Journal of Applied Research in Intellectual Disabilities*, 00:1–11.

McKearney, Patrick, ‘Challenging care: professionally not knowing what good care is’, (2020), vol 45(2), *Anthropology and Humanism*, pp 223–32

McKearney, Patrick, ‘What escapespPersuasion: why intellectual disability troubles ‘dependence’ in liberal societies’, (2021), vol 40(2), *Medical Anthropology*, pp 155–68

McSherry, Bernadette, ‘Mental health laws: where to from here’, (2014), vol 40, *Monash University Law Review*, pp 175–97

McSherry, Bernadette & Kay Wilson, ‘The concept of capacity in Australian mental health law reform: Going in the wrong direction?’ (2015), vol 40, *International Journal of Law and Psychiatry* pp, 60–69

Meltzer, Ariella Sally Robinson, Yvette Proud & Karen R Fisher, *Literature and practice review: support to make decisions that promote personal safety and prevent harm*, Social Policy Research Centre UNSW, 2016.

Mental Health Australia & ACT Disability Aged and Carer Advocacy Service (ADACAS), ‘Fact sheet. Supported Decision Making, Psychosocial Disability and the National Disability Insurance Scheme*’* (2016) https://mhaustralia.org/sites/default/files/docs/supported_decision_making_fact_sheet.pdf

Mental Welfare Commission for Scotland. *Mental Health Act Monitoring Report 2018–2019*. Edinburgh. https://www.mwcscot.org.uk/sites/default/files/2019-10/MHA-MonitoringReport-2019_0.pdf

Merfin-Veitch, Brigit, *Exploring article 12 of the United Nations Convenion on the Rights of Persons with Disabilities: An integrtive literature review*, Donald Beasley Institute, 2016.

Miller, Lyndsey M, Christopher S Lee, Carol J Whitlatch & Karen S Lyons, ‘Involvement of hospitalized persons with dementia in everyday decisions: A dyadic study’, (2018), vol 58(4), pp *The Gerontologist*, pp 644–53

Miller, Lyndsey M, Carol J Whitlatch & Karen S Lyons, ‘Shared decision-making in dementia: A review of patient and family carer involvement’, (2016), vol 15(5), *Dementia,* pp 1141–57

Minkowitz, Tina, ‘CRPD Article 12 and the Alternative to Functional Capacity: Preliminary Thoughts Towards Transformation’ (2013)

Minkowitz, Tina, *Norms and Implementation of CRPD Article 12 (September 18, 2010).* Available at SSRN: https://ssrn.com/abstract=2037452 or http://dx.doi.org/10.2139/ssrn.2037452 (2020)

Mintz, Kevin T & David C Magnus, ‘Disability, aging, and the Importance of recognizing social supports in medical decision making’, (2021), vol 21(11), *The American Journal of Bioethics*, pp 1–3

Montoya, Therése Fridström, *Supported Decision-Making in Swedish Law – Is the »Good Man« a Good or Bad Guy in Light of the CRPD?*, Psychiatrie Verlag, 2019.

Moore, Sophie, Rebecca Wotus, Alyson Norman, Mark Holloway & Jackie Dean, ‘Behind the cloak of competence: brain injury and mental capacity legislation’, (2019), vol 21(4), *The Journal of Adult Protection*, pp 201–18

Morrissey, Fiona, ‘The United Nations Convention on the Rights of Persons with Disabilities: a new approach to decision-making in mental health law’, (2012), vol 19(5), *European Journal of Health Law*, pp 423–40

Murphy, Joan & Tracey Oliver, ‘The use of Talking Mats to support people with dementia and their carers to make decisions together’, (2013), vol 21(2), *Health & Ssocial Care in the Community*, pp 171–80

Nadakavukaren Schefer, K, Terry Carney, R Cera, J Curran, S De Dycker, V Kühnel, J Lespérance, M Schulze, A Vasquez, C Viennet & H Westermark, *Persons with disabilities’ right to autonomy and their right to vote: Australia, Austria, Canada, France, Germany, Italy, the Netherlands, New Zealand, Norway, Spain, Sweden, United Kingdom, United States*, Swiss Institute of Comparative Law, 2019.

Naeem, Iffat & Tanvir Chowdhury Turin, ‘Ethical dilemmas and legal ambivalence affects the midwives’ perception for providing sexual and reproductive health consultation to women with intellectual disability’, (2021), vol 24(2), *Evidence-based Nursing*, pp 49–49

National Disability Insurance Agency, ‘Companion Paper: Supporting you to make your own decisions’, <file:///C:/Users/julia/Downloads/PB%20ER%20Support%20decision%20consult%20companion%20PDF.pdf>

National Disability Insurance Agency, *National Disability Insurance Scheme Consultation Paper: Supporting you to make your own decisions,* 2021.

National Disability Services, ‘People with Disability and Supported Decisoin-Making in the NDIS: A Guide for NSW Providers’ (20xx) https://www.nds.org.au/resources/people-with-disability-and-supported-decision-making-in-the-ndis-a-guide-for-nsw-providers

National Health and Medical Research Council, Australian Research Council & Universities Australia, *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*, National Health and Medical Research Council, 2007, updated 2018

Nedlund, Ann-Charlotte & Annika Taghizadeh Larsson, ‘To protect and to support: How citizenship and self-determination are legally constructed and managed in practice for people living with dementia in Sweden, (2016), vol 15(3), *Dementia*, pp 343–357

NSW Government Department of Family & Community Services (FACS), ‘Supported Decision-making. A handbook for facilitators’ (2019)

https://www.ideas.org.au/books/supported-decision-making-a-handbook-for-facilitators.html

New South Wales Law Reform Commission, ‘Review of the Guardianship Act 1987’ Report, (May 2018)

Newbigging, Karen, Julie Ridley, Mick McKeown, Karen Machin & Konstantina Poursanidoul, ‘‘When you haven’t got much of a voice’: An evaluation of the quality of Independent Mental Health Advocate (IMHA) services in England’, (2015), vol 23(3), *Health & Social Care in the Community*, pp 313–324

Newton-Howes, Giles & Sarah Gordon, ‘Who controls your future: the Convention on the Rights of Persons with Disabilities from a service user focused perspective’, (2020) ,vol 54(2), *Australian and New Zealand journal of Psychiatry*, pp 134–137

Nidus Personal Planning Resource Centre and Registry, *Experiences of Adults Living with Fetal Alcohol Spectrum Disorder and their Personal Supporters in Making and Using a Representation Agreement*, http://www.nidus.ca/PDFs/Nidus_Research_RA_FASD_Project.pdf

Norman, Alyson, Sophie Moore, Rebecca Wotus, Mark Holloway & Jackie Dean, *Supported Decision Making: Brain injury case managers' experience of mental capacity and the Mental Capacity Act* (Technical Report, February 2018) DOI: 10.13140/RG.2.2.35575.73128

Nunnelley, Sophie, *Personal Support Networks in Practice and Theory: Assessing the Implications for Supported Decision-Making Law*, Law Commission of Ontario, 2015.

O'Donnell, Deirdre, Éidín Ní Shé, Carmel Davies, Sarah Donnelly, Therese Cooney, Diarmuid O›Coimin, Diarmuid O›Shea, Lorraine Kyne, Diarmaid O›Sullivan, Bernadette Rock, Marie O›Shea, Eilish McAuliffe, Ann O›Shaughnessy & Thilo Kroll, 'Promoting assisted decision-making in acute care settings for care planning purposes: Study protocol', (2018), vol 1, *HRB Open Research* 2, 2 https://doi.org/10.12688/hrbopenres.12797.1

Office of the Public Advocate (Qld), *Decision-making Support and Queensland's Guardianship System: A Systemic Advocacy Report*, 2016.

Office of the Public Advocate (Vic), 'Decision Time: Activating the rights of adults with cognitive disability', file:///C:/Users/julia/Downloads/OPA%20Decision%20TIme.pdf

Office of the Public Advocate (Vic), 'Guide to NDIS decision-making. When a decision can be made by, with, or for an adult with significant cognitive disability', 2018.

Office of the Public Advocate (Vic), 'Side by Side: a guide for people wanting support to make decisions', 2018

Office of the Public Advocate (Vic), 'Supported decision-making in Victoria', 2020

Office of the Public Advocate (Vic), 'Walk with me, talk with me: a practice guide for OPA staff '2018

Office of the Publicate Advocate (Vic) & VALID, *Volunteer Programs of Support for Decision-Making: Lessons and recommendations from the OVAL Project*, VALID and Office of the Public Advocate, 2017

O'Mahony, Charles & Catriona Maloney, 'The impact of international human rights law on Irish mental health and mental capacity law reform', (2017), vol 23, *Medico-Legal Journal of Ireland,* p 24.

Osterholm, J H, A T Larsson & A Olaison, 'Handling the Dilemma of Self-Determination and Dementia: A Study of Case Managers' Discursive Strategies in Assessment Meetings', (2015), vol 58(6), *Journal of Gerontological Social Work*, pp 613–36.

Ottmann, G, K McVilly & M Maragoudaki, ''I walk from trouble': exploring safeguards with adults with intellectual disabilities – an Australian qualitative study' (2016), vol 31(1), *Disability & Society*, pp 47–63

Pathare, Soumitra & Arjun Kapoor, 'Decisional autonomy and India's Mental Healthcare Act, 2017: a comment on emerging jurisprudence' in Faraaz Mahomed, Michael Ashley Stein, Vikram Patel & Charlene Sunkel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 155–70

Peisah, Carmelle, Oluwatoyin A Sorinmade, Leander Mitchell & Cees M P M Hertogh, 'Decisional capacity: toward an inclusionary approach', (2013), vol 25(10), *International Psychogeriatrics*, pp 1571–79

Pell, Elizabeth & Virginia Mulkern, *Supported Decision-Making Pilot: Pilot Program Evaluation Year 2 Report*, Center for Public Representation and Nonotuck Resource Associates, Inc, 2016

Pell, Elizabeth, *Supported Decision-Making New York: Evaluation Report of an Intentional Pilot*, Hunter College, CUNY, 2019.

Penzenstadler, Louise, Andrew Molodynski & Yasser Khazaal, ‘Supported decision making for people with mental health disorders in clinical practice: a systematic review’, (2020), vol 24(1), *International Journal of Psychiatry in Clinical Practice*, pp 3–9

Perry, Elyse, Rebecca Waters & Angus Buchanan, ‘Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability’, (2019), vol 54(3,) *The Australian Journal of Docial Issues*, pp 210–23

Perske, Robert, ‘The dignity of risk’, in W Wolfensberger et al (ed) *The principle of normalization in human services*, National Institute of Mental Retardation, 1972, pp 194–200

Peterson, Andrew, Jason Karlawish & Emily Largent, ‘Supported Decision Making With People at the Margins of Autonomy’, (2020,) *The American Journal of Bioethics*, pp 1–21

Phillips, John & David Wendler, ‘Clarifying substituted judgement: the endorsed life approach: Table 1’, (2015), vol 41(9), *Journal of Medical Ethics*, pp 723–30

Phuong, Do Lan, ‘How well does the Australian National Disability Insurance Scheme respond to the issues challenging Indigenous people with disability*?*’, (2017), vol 29(4), *Aotearoa New Zealand Association of Social Workers*, pp 49–60

Picton, Alison, ‘Decision-making support for inpatients with learning disabilities’, (2011), vol 107(32–33), *Nursing Times*, pp 12–14

Plater, David, Lukas Price, Esther Richards & Mark Giancaspro, ‘New avenues of providing effective care: the role of microboards’, (2021), vol 43(6), *The Bulletin: The Law Society of South Australia Journal*, pp 9–11

Plumb, Anne, ‘UN Convention on the Rights of Persons with Disabilities: out of the frying pan into the fire? Mental health service users and survivors aligning with the disability movement ‘ in Helen Spandler, Jill Anderson & Bob Sapey (ed) *Madness, Distress and the Politics of Disablement*, Bristol University Press, 2015, pp 183–98

Pritchard-Jones, Laura, ‘Exploring the potential and the pitfalls of the United Nations Convention on the Rights of Persons with Disabilities and General Comment No. 1 for people with dementia’, (2019), vol 66, *International Journal of Law and Psychiatry*, 101467: 1–7

Proud, Yvette, *Standing strong in stormy weather: supporting decision making and problem solving using the ‘Tree of Life’ practice guide*, NSW Council of Social Service, 2018;

Purcal, Christiane, Trish Hill, Kelley Johnson & Rosemary Kayess, ‘Evaluation of the Supported Decision Making Phase 2 (SDM2) project: Final report’ (Prepared for: NSW Trustee and Guardian with the NSW Public Guardian, May 2017)

Ries, Nola M & Elise Mansfield, ‘Advance Research Directives: Dementia Researchers’ Views on a Prototype Directive and Implementation Strategies’, (2021), vol 43(3), *Ethics & Human Research*, pp 10–25

Ries, Nola M, Elise Mansfield & Rob Sanson-Fisher, ‘Ethical and legal aspects of research involving older people with cognitive impairment: a survey of dementia researchers in Australia’, (2020), vol 68, *International Journal of Law and Psychiatry*, 101534

Roche, Brian, *Report: To investigate if supported decision making will reduce elder financial abuse in Australia*, Winston Churchill Memorial Trust, 2018

Roper, Cath, 'Capacity Does not Reside in me' in Claire Spivakovsky, Kate Seear & Adrian Carter (ed), *Critical Perspectives on Coercive Interventions*, Routledge, 2018, pp 85–9

Royal Commission into Aged Care, Quality and Safety, *Dementia in Australia: Nature, Prevalence and Care: Background Paper 3*, 2019)

Ryrstedt, Eva, 'Dementia and autonomy' in Ann Numhauser-Henning (ed) *Elder Law: Evolving European Perspectives*, Edward Elgar Publishing, 2017, pp 358–78

Samsi, Kritika & Jill Manthorpe, 'Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers', (2013), vol 25(6), *International Psychogeriatrics*, pp 949–61

Savery, Jonathon, 'Voting rights and intellectual disability in Australia: an Jonathon Savery, 'Voting rights and intellectual disability in Australia: an illegal and unjustified denial of rights', (2015), vol 37(2), *The Sydney Law Review*, pp 287–300

Schindler, Michael & Meytal Segal-Reich, 'Supported decision-making for older persons in Israel: the 2015 precedent and the following 2016 regulation', (2016), vol 10, *Elder Law Review (University of Western Sydney)* pp 1–21.

Schmitten, Jürgen, Ralf J Jox, Michael Pentzek & Georg Marckmann, 'Advance care planning by proxy in German nursing homes: Descriptive analysis and policy implications', (2021), vol 69(8), *Journal of the American Geriatrics Society (JAGS)* 2122–2131

Schneiders, Christopher, Elyn R Saks, Jonathan Martinis & Peter Blanck,, 'Psychiatric advance directives and supported decision-making: preliminary developments and pilot studies in California' in Faraaz Mahomed, Michale Ashley Stein, Vikram Patel & Charlene Sunkel (ed) *Mental health, legal capacity, and human rights*, Cambridge University Press, 2021, pp 288–301

Scholten, Matthé & J Gather, 'Adverse consequences of article 12 of the UN Convention on the Rights of Persons with Disabilities for persons with mental disabilities and an alternative way forward', (2018), vol 44(4), *Journal of Medical Ethics*, pp 226–33

Scholten, Matthé, Esther Braun, Jakov Gather & Jochen Vollmann, 'Combining supported decision-making with competence assessment: a way to protect persons with impaired decision-making capacity against undue influence,' (2021), vol 21(11), *The American Journal of Bioethics*, pp 45–47

Scottish Independent Advocacy Alliance, *Principles and Standards for Independent Advocacy*. Scottish Independent Advocacy Alliance, 2008.

Scottish Mental Health Law Review, 'Interim Report', <https://cms.mentalhealthlawreview.scot/wp-content/uploads/2021/07/Scottish-Mental-Health-Law-Review-Interim-Report-July-2021.pdf>

Series, Lucy, Anna Arstein-Kerslake & Elizabeth Kamunida, 'Legal capacity: a global analysis of reform trends' in Peter Blanck and Eilionoir Flynn (ed), *Routledge Handbook of Disability Law and Human Rights* Routledge, 2016, pp 137–55

Series, Lucy & A Nilsson, ‘Article 12 CRPD: Equal recognition before the law’ in I Bantekas, M A Stein and D Anastasiou (ed), *The UN Convention on the Rights of Persons with Disabilities: A Commentary*, Oxford University Press, 2018, pp 340–79; Shouli Shahid, Emma V Taylor, Shelley Cheetham, John A Woods, Samar M Aoun & Sandra C Thompson, ‘Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: a comprehensive review’, (2018,) vol 17(1), *BMC Palliative Care*, 72: 1–2d

Shapiro, Devora, Lauren R Sankary & Paul J Ford, ‘Reconciling supported decision making with shared Decision making in the context of potential vulnerability’, (2021), vol 21(11), *The American Journal of Bioethics*, pp 35–37

Sharad, Philip, Subhashini Rangarajan, Sydney Moirangthem, Channaveerachari Kumar, Mahesh Gowda, Guru Gowda & Suresh Math, ‘Advance directives and nominated representatives: a critique’, (2019), vol 61(10), *Indian Journal of Psychiatry*, pp 680–85.

Shogren, Karrie, Graham G Rifenbark, Michael L Wehmeyer, Evan E Dean, Mary B Killeen & Judith Karsevar, ‘Refining the Supported Decision Making Inventory’, (2020), vol 17(3), *Journal of Policy and Practice in Intellectual Disabilities*, pp 195–206

Shogren, Karrie A, Michael L Wehmeyer, Susan B Palmer, Anjali J Forber-Pratt, Todd J Little & Shane Lopez, ‘Causal agency theory: reconceptualizing a functional model of self-determination’, (2015), vol 50(3), *Education and Training in Autism and Developmental Disabilities*, pp 251–63.

Shogren, Karrie A, Michael L Wehmeyer, H Uyanik & M Heidrich, ‘Development of the Supported Decision Making Inventory System’, (2017), vol 55(6), *Intellectual and Developmental Disabilities*, pp 432–439

Shogren, Karrie Ann, Michael L Wehmeyer, Jonathan Martinis & Peter David Blanck, *Supported decision-making: theory, research, and practice to enhance self-determination and quality of life*, Cambridge University Press, 2019.

Simard, Joyce & Ladislav Volicer, ‘Loneliness and isolation in long-term care and the COVID-19 pandemic’, (2020), vol 21(7), *Journal of the American Medical Directors Association*, pp 966–67.

Simmons, M B & Piers Gooding, ‘Spot the difference: Shared decision-making and supported decision-making in mental health’, (2017), vol 34(4), (10/23), *Irish Journal of Psychological Medicine* 275–86

Sinclair, Craig, Julie Bajic-Smith, Meredith Gresham, Meredith Blake, Romola S Bucks, Sue Field, Josephine M Clayton & Helen Radoslovich, ‘Professionals’ views and experiences in supporting decision-making involvement for people living with dementia’, (2021), vol 20(1), *Dementia - International Journal of Social Research and Practice*, pp 84–105.

Sinclair, Craig, Meredith Blake & Sue Field, *Supported decision-making in aged care: A policy development guideline for aged care providers in Australia,* Cognitive Decline Partnership Centre, 2018.

Sinclair, Craig, Sue Field, Meredith Blake & Helen Radoslovich ‘An examination of organisational policies for healthcare and lifestyle decision-making among Australian aged care providers’, (2019), vol 38(S2), *Australasian Journal on Ageing*, pp 90–7.

Sinclair, Craig, Kate Gersbach, Michelle Hogan, Meredith Blake, Romola Bucks, Kirsten Auret, Josephine Clayton, Cameron Stewart, Sue Field, Helen Radoslovich, Meera Agar, Angelita Martini, Meredith Gresham, Kathy Williams & Sue Kurrle, ‘“A Real Bucket of Worms”: views of people living with dementia and family members on upported decision-making’, (2019), vol 16(4), *Journal of Bioethical Inquiry*, pp 587–608.

Sinclair, Craig, Kate Gersbach, Michelle Hogan, Romola S Bucks, Kirsten A Auret, Josephine M Clayton, Meera Agar & Sue Kurrle, ‘How couples with dementia experience healthcare, lifestyle, and everyday decision-making’, (2018), vol 30(11), *International Psychogeriatrics*, pp 1639–47

Sinclair, Craig, Susan Kurrle, Sue Field, Meera Agar, Kathy Williams, Romola Bucks, Josephine Clayton, Cameron Stewart, Meredith Blake, Kirsten Auret, Meredith Gresham, Angelilta Martini & Helen Radoslovich, *Supported decision-making in dementia care: Final project report*, NHMRC Cognitive Decline Partnership Centre, 2019

Sinclair, Craig, Marcus Sellars, Kimberly Buck, Karen Detering, Ben White & Linda Nolte ‘New geriatrics and gerontology findings reported from Austin Health (Association between region of birth and advance care planning documentation among older Australian migrant communities: A multi-center audit study)’ (2020) *Medical Letter on the CDC & FDA*, pp 1717–1717

Sinclair, Criag, K Auret, S F Evans, F Williamson, S Dormer, A Wilkinson, K Greeve, A Koay, D Price & F Brims, ‘Advance care planning uptake among patients with severe lung disease: A randomised patient preference trial of a nurse-led, facilitated advance care planning intervention’, (2017), vol 7(2), *BMJ Open* e013415–e013415

Skowron, Paul, ‘Giving substance to ‘the best interpretation of will and preferences’’ (2019), vol 62, *International Journal of Law and Psychiatry*, pp 125–34

Smebye, Kari Lislerud, Marit Kirkevold & Knut Engedal, ‘How do persons with dementia participate in decision making related to health and daily care? A multi-case study’ (2012), vol 12(1), *BMC Health Services Research,* pp 241–24

Smith, Anita & Danny Sullivan, ‘A new ball game: the United Nations Convention on the Rights of Persons with Disabilities and assumptions in care for people with dementia,’ (2012), vol 20(1), *Journal of Law and Medicine*, pp 28–34

Smith, Elizabeth, Tessa-May Zirnsak, Jennifer Power, Anthony Lyons & Christine Bigby, ‘Social inclusion of LGBTQ and gender diverse adults with intellectual disability in disability services: A systematic review of the literature’, (2021), *Journal of Applied Research in Intellectual Disabilities*, DOI: 10.1111/jar.12925

Snelling, Jeanne, ‘Sexual health, reproductive liberty and adults with impaired capacity’ in Iris Reuvecamp and John Dawson (eds), *Mental Capacity Law in New Zealand* Thomson Reuters, 2019, pp 251–65.

Snelling, Jeanne & Alison Douglass, ‘Legal capacity and supported decision-making’ in Iris Reuvecamp & John Dawson (ed), *Mental Capacity Law in New Zealand*, Thomson Reuters, 2019, pp 163–77.

Social Policy Research Centre, *Skilled to thrive: support to make decisions that promote personal safety and prevent harm*, Social Policy Research Centre UNSW, 2017.

Soldatic, Karen, Georgia van Toorn, Leanneand Dowse & Kirsty Muir, ‘Intellectual Disability and Complex Intersections: Marginalisation under the National Disability Insurance Scheme’, (2014), vol 1(1), *Research and Practice in Intellectual and Developmental Disabilities,* pp 6–16.

Spivakovsky, Claire, ‘Barriers to the NDIS for people with intellectual disability and/or complex support needs involved with the criminal justice systems: The current state of literature ‘ (2021, in press) *Journal of Intellectual and Developmental Disability*

Stainton, Tim, ‘Supported decision-making in Canada: Principles, Policy, and Practice’, (2016), vol 3(1), *Research and Practice in Intellectual and Developmental Disabilities*, pp 1–11

State of Victoria, Department of Health, *Mental Health and Wellbeing Act: Update and engagement paper*, State of Victoria, Department of Health, June 2021.

Stavert, Jill, ‘The exercise of legal capacity, supported decision-making and Scotland’s mental health and incapacity legislation: working with CRPD challenges’, (2015), vol 4(2), *Laws*, pp 296-313

Stavert, Jill, ‘Paradigm shift or paradigm paralysis? National mental health and capacity law and implementing the CRPD in Scotland’, (2018), vol 7(3), *Laws*, pp 26–41

Stavert, Jill, ‘Supported decision-making and paradigm shifts: word play or real change?’, (2020), vol 11, *Frontiers in Psychiatry*, 571005–571005

Stone, Meredith, Renata Kokanovic, Felicity Callard & Alex F Broom, ‘Estranged relations: coercion and care in narratives of supported decision-making in mental healthcare’, (2020), vol 46(1), *Medical Humanities*, pp 62–72.

Strickland, Karen, Kasia Bail, Sarah Cope, Murray Turner & Cameron Moss, ‘Supported decision-making to assist older persons experiencing elder abuse: An integrative review’, (2021), vol 28(4), *Collegian*, pp 447–55.

Sugiura, Kanna, Faraaz Mahomed, Shekhar Saxena & Vikram Patel, ‘An end to coercion: rights and decision-making in mental health Health, (2020), vol 98(1), (10/17), *Bulletin of the World Health Organization*, pp 52–8.

Sullivan, William F & John Heng, ‘Supporting adults with intellectual and developmental disabilities to participate in health care decision making’, (2018), 64(Suppl 2), *Canadian Family Physician Medecin de Famille Canadien*, pp S32–S36.

Szmukler, George, ‘’Capacity’, ‘best interests’, ‘will and preferences’ and the UN Convention on the Rights of Persons with Disabilities’, (2019), vol 18(1), *World Psychiatry*, pp 34–41.

Taghizadeh Larsson, Annika & Johannes H Österholm, ‘How are decisions on care services for people with dementia made and experienced? A systematic review and qualitative synthesis of recent empirical findings’, (2014), vol 26(11), *International Psychogeriatrics*, pp 1849–62

Tarzia, Laura, Deirdre Fetherstonhaugh & Michael Bauer, ‘Dementia, sexuality and consent in residential aged care facilities’, (2012), vol 38(10), *Journal of Medical Ethics: Journal of the Institute of Medical Ethics*, pp 609–13

Tasmanian Law Reform Institute, ‘Review of the *Guardianship and Administration Act 1995* (Tas)’ <www.utas.edu.au/law-reform/publications>

Taylor, Whitney D, Virginie Cobigo & Hélène Ouellette-Kuntz, ‘A famidy systems perspective on supporting self-determination in young adults with intellectual and developmental Disabilities’, (2019), vol 32(5), *Journal of Applied Research in Intellectual Disabilities*, pp 1116–28

The Arc of Arizona, *Supported Decision Making and You: Your Curriculum Guide on Supported Decision Making* (undated)

The Arc of Northern Virginia (The Arc) & The Burton Blatt Institute at Syracuse University (BBI), ‘“I learned that I have a voice in my future”: Summary, Findings, and Recommendations of the Virginia Supported Decision-Making Pilot Project’, http://www.supporteddecisionmaking.org/sdm-va-report-findings-2021

The Health Foundation, *Person-centred care made simple: What everyone should know about person-centred care* (2016)

Then, Shih-Ning, ‘Evolution and innovation in guardianship laws: assisted decision-making’, (2013), vol 35(1) *Sydney Law Review*, pp 133–66

Then, Shih-Ning, Hilary Patrick & Nicola Smith, ‘Reinforcing guardianship regimes through assisted decision making - a Scottish perspective,’ (2014), vol 4, *The Juridical Review*, pp 263–80

Then, Shih-Ning, Terry Carney, Christine Bigby & Jacinta Douglas, ‘Supporting decision-making of adults with cognitive disabilities: The role of Law Reform Agencies – recommendations, rationales and influence’, (2018), vol 61, *International Journal of Law and Psychiatry*, pp 64–75

Shih-Ning Then, Terry Carney, Christine Bigby, Ilan Wiesel, Elizabeth Smith & Jacinta Douglas, ‘Moving from support for decision-making to substitute decision-making: legal frameworks and perspectives of supporters of adults with intellectual disabilities’, (2022), vol 37(3), *Law in Context,* doi.org/10.26826/law-in-context.v37i3.174

Theodorou, Eliana J, ‘Supported decision-making in the lone-star State’, (2018), vol 93(4), *New York University Law Review*, pp 973–1013

Tilse, Cheryl & Jill Wilson, ‘Recognising and responding to financial abuse in residential aged care’, (2013), vol 15(3), *The Journal of Adult Protection*, pp 141–52

Tilse, Cheryl, Jill Wilson, Linda Rosenman, David Morrison & Anne-Louise McCawley, ‘Managing older people’s money: assisted and substitute decision making in residential aged-care’, (2011), vol 31(1), *Ageing & Society*, pp 93–109.

Tracy, Jane, ‘Supporting Nick to make decisions: an exploration of ways to promote choice and control’, (2015), vol 2(1), *Research and practice in intellectual and developmental disabilities,* pp 29–36

Tune, David, *Review of the National Disability Insurance Scheme Act 2013; Removing red tape and implementing the NDIS participant service guarantee* (2019), pp 13 NDIS Act Review - final - with accessibility and prepared for publishing1 (dss.gov.au)

Vanegas, Sandra B, Sandy Magaña, Weiwen Zeng & Carlos Pavon, ‘Decision making and culturally diverse individuals with IDD and their families: A call for research’ in Ishita Khemka & Linda Hickson (ed) *Decision Making by Individuals with Intellectual and Developmental Disabilities: Integrating Research into Practice*, Springer International Publishing, 2021, pp 221-51

VanPuymbrouck, L, *Supported Decision Making in the United States: A White Paper*, Council on Quality and Leadership, 2017 https://www.c-q-l.org/wp-content/uploads/2019/12/CQL-2017-White-Paper-Supported-Decision-Making-In-The-US.pdf

Verlenden, Jorge V, Jeanne Bertolli & Lee Warner, ‘Contraceptive practices and reproductive health considerations for adolescent and adult women with intellectual and developmental disabilities: a review of the literature’, (2019), vol 37, *Sexuality and Disability*, pp 541–57

Victorian Government Department of Human Services (DHS), ‘Supporting decision-making. A guide to supporting people with a disability to make their own decisions’, (2012)

Victorian Law Reform Commission, ‘Guardianship: Final Report’ <www.lawreform.vic.gov.au>

Waite, Katherine R, Alex D Federman, Danielle M McCarthy, Rebecca Sudore, Laura M Curtis, David W Baker, Elizabeth A H Wilson, Romana Hasnain-Wynia, Michael S Wolf & Michael K Paasche-Orlow, ‘Literacy and race as risk factors for low rates of advance directives in older adults’, (2013), vol 61(3), *Journal of the American Geriatrics Society (JAGS)* pp 403–6,

Watson, J, H Voss & M J Bloomer, ‘Placing the preferences of people with profound intellectual and multiple disabilities at the center of end-of-life decision making through storytelling’, (2019), vol 44(4), *Research and Practice for Persons with Severe Disabilities*, pp 267–79

Watson, Joanne, ‘Assumptions of decision-making capacity: the role supporter attitudes ay in the realisation of article 12 for people with severe or profound intellectual disability’ (2016), vol 5(6), *Laws*, doi:10.3390/laws5010006

Watson, Joanne, Erin Wilson & Nick Hagiliassis, ‘Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability’, (2017), vol 30(6), *Journal of Applied Research in Intellectual Disabilities*, pp 1022–1034

Webb, Paul, Gavin Davidson, Rosalie Edge, David Falls, Fionnuala Keenan, Berni Kelly, Aisling McLaughlin, Lorna Montgomery, Christine Mulvenna, Barbara Norris, Aine Owens & Rebecca Shea Irvine, ‘Key components of supporting and assessing decision making ability’, (2020), vol 72, *International Journal of Law and Psychiatry*, 101613

Webb, Paul, Gavin Davidson, Rosalie Edge, David Falls, Fionnuala Keenan, Berni Kelly, Aisling McLaughlin, Lorna Montgomery, Christine Mulvenna, Barbara Norris, Aine Owens & Rebecca Shea Irvine, ‘Service users’ experiences and views of support for decision-making’, (2020), vol 28(4), *Health & Social Care in the Community,* pp 1282-91

Werner, Shirli & Rachel Chabany, ‘Guardianship law versus supported decision-making policies: perceptions of persons with intellectual or psychiatric disabilities and parents’ (2016), vol 86(5), *American Journal of Orthopsychiatry*, pp 486–99

Western Australia’s Individualised Services (WAIS), ‘Supported Decision-making’ (20xx) https://waindividualisedservices.org.au/wp-content/uploads/2019/02/WAIS0008_4-Booklets-in-One-May15.pdf

WestWood Spice for the Department of Community and Family Services, *My life, my decision: An independent evaluation of the supported decision making pilot*, New South Wales Government Department of Community and Family Services, 2015

White Ben, Lindy Willmott, C Cartwright, Malcolm Parker & G Williams, ‘Doctors’ knowledge of the law on withholding and withdrawing life-sustaining medical treatment’, (2014), vol 201(4), *Medical Journal of Australia*, pp 229–32

White Ben, Lindy Willmott, C Cartwright, Malcolm Parker & G Williams, ‘Knowledge of the law about withholding or withdrawing life-sustaining treatment by intensivists and other specialists’, (2016), vol 18(2), *Critical Care and Resuscitation*, pp 109–115

White, Ben, Lindy Willmott & Shih-Ning Then, ‘Chapter 7: Adults who lack capacity: substitute decision making’ in Ben White, Fiona McDonald & Lindy Willmott (ed), *Health Law in Australia*, Lawbook Co, 3rd ed, 2018, pp 207–70

Wied, Theresa, A Poth, J Pantel, F Oswald, J Haberstroh & Ensure Consortium, ‘How do dementia researchers view support tools for informed consent procedures of persons with dementia?’ (2020) *Zeitschrift Fur Gerontologie Und Geriatrie* https://doi.org/10.1007/s00391-020-01779-2

Wied, Theresa S, Maren Knebel, Valentina A Tesky & Julia Haberstroh, ‘The human right to make one’s own choices – implications for supported decision-making in persons with dementia: A systematic review’, (2019), vol 24(2), *European Psychologist*, pp 146–58

Wied, Theresa, Matthe Scholten, Julia Haberstroh & Johanne Pantel, ‘Supported decision-making in persons with dementia: Development of an enhanced consent procedure for lumbar puncture, https://www.researchgate.net/profile/Matthe-Scholten/publication/356266883_

Wiesel, Ilan, Elizabeth Smith, Christine Bigby, Shih-Ning Then, Jacinta Douglas & Terry Carney, ‘The temporalities of supported decision-making by people with cognitive disability,’ (2020), *Social & Cultural Geography*, DOI: 10.1080/14649365.2020.1829689

Wildeman, Sheila M, ‘Consent to psychiatric treatment: from insight (into illness) to incite (a riot)’ in Colleen Flood and Jennifer Chandler (ed) *Law and Mind: Mental Health Law and Policy in Canada,* LexisNexis, 2016.

Wilkins, James M, ‘More than capacity: Aaternatives for sexual decision making for individuals with dementia’, (2015), vol 55(5), *The Gerontologist*, pp 716–23

Wilson, Erin, Robert Campain, Sarah Pollock, Lisa Brophy & Anthony Stratford,, ‘Exploring the personal, programmatic and market barriers to choice in the NDIS for people with psychosocial disability’, (2021), *Australian Journal of Sociological Issues,* pp 1–21.

Wilson, Kay, *Mental health law: Abolish or reform?*, Oxford University Press, 2021.

Wilson, Nathan J, Jemima Macdonald, Brenda Hayman, Alexandra M Bright, Patsie Frawey & Gisselle Gallego, ‘A narrative review of the literature about people with intellectual disability who identify as lesbian, gay, bisexual, transender, intersex or questioning’, (2018), vol 22(2), *Journal of Intellectual Disabilities,* pp 171–96

Winkler, Dianne, Libby Callaway, Sue Sloan & Nadine Holgate, ‘Everyday choice making: outcomes of young people with acquired brain injury after moving from residential aged care tocCommunity-based supported accommodation’, (2015), vol 16(3), *Brain impairment*, pp 221–35

World Health Organization, *Supported decision-making and advance planning: WHO QualityRights specialized training: course guide* (2019)

Wright, Megan, ‘Dementia, cognitive transformation, and supported decision making’, (2020), vol 20(8), *American Journal of Bioethics*, pp 88–90

Wright, Megan S, ‘Dementia, healthcare decision making, and disability law’, (2019), vol 47(S 4), *The Journal of Law, Medicine & Ethics: A Journal of the American Society of Law, Medicine & Ethics*, pp 25–33

Wright, Megan S, ‘Equality of autonomy? Physician aid in dying and supported decision-making’, (2021), vol 63(1), *Arizona Law Review,* pp 157–98

Zannettino, Lana, Dale Bagshaw, Sarah Wendt & Valerie Adams, ‘The role of emotional vulnerability and abuse in the financial exploitation of older people from culturally and linguistically diverse communities in Australia’ (2015), vol 27(1), *Journal of Elder Abuse & Neglect*, pp 74–89

Zhang, Dalun, Jessica M Walker, Dianey R Leal, Leena Jo Landmark & Antonis Katsiyannis, ‘A call to society for supported decision-making: theoretical and legal reasoning’, (2019), vol 28(7), *Journal of Child and Family Studies*, pp 1803–14

Zinkler, Martin, ‘Supported decision making in the prevention of compulsory interventions in mental health care’, (2019), vol 10(137), *Frontiers in Psychiatry*, doi: 10.3389/fpsyt.2019.00137

Legislation

Adult Guardianship and Trusteeship Act 2008 (A)

Assisted Decision-Making (Capacity) Act 2015 (Ireland)

Civil Code 1991 (Q)

Commonwealth Electoral Act 1918 (Cth)

Decision-making, Support and Protection to Adults Act 2003 (Y)

Guardianship and Administration Act 2019 (Vic)

Medical Treatment Planning and Decisions Act 2016 (Vic)

Mental Capacity Act 2005 (England and Wales)

Mental Capacity Act 2016 (Northern Ireland)

Mental Health Act 2015 (ACT)

Powers of Attorney Act 1998 (Qld)

Representation Agreement Act 1996 (BC)

UN documents and instruments

Committee on the Rights of Persons with Disabilities, *General Comment No. 1 Article 12: Equal Recognition Before the Law* UN Doc CRPD/C/GC/1 (19 May 2014)

Committee on the Rights of Persons with Disabilities, *Concluding observations on the combined second and third reports of Australia (Advance Unedited Version)*, UN Doc CRPD/C/AUS/CO/2-3)

Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 2515 UNTS 15 (entered into force 3 May 2008)

Appendix B

Recent initiatives and programs: report of online survey results

Ilan Wiesel, Christine Bigby, Craig Sinclair, Julia Duffy, Terry Carney, Shih-Ning Then and Jacinta Douglas.

Introduction

This appendix presents a table of recent initiatives and programs in Australia aimed at enhancing supported decision-making and the objectives of Article 12. Information about these programs was collected through an online questionnaire, which was sent by email through the research team's Australian and international professional networks. The questionnaire asked respondents to list and briefly describe initiatives they are aware of in recent years, with a focus on the last 5 years. The questionnaire asked about initiatives both in Australia and internationally, however because of limited coverage of international initiatives, the table is exclusively focused on Australia. Beyond survey responses, additional information was collected through online desktop research. Initiatives that were not mentioned by survey respondents but identified through our literature review (Appendix A to the Report), were also included in the table. Where a publicly available evaluation or peer-reviewed article on an initiative was identified, a link or reference to the report is included in the table. Although the table does not comprehensively cover all supported decision-making initiatives in Australia in recent years, it offers a useful broad overview of relevant activity in the sector.

Table 1 – survey results on recent initiatives and programs

State	Initiative	Leading organization	Brief description	Links and references
South Australia	Living My Life	SAMHRI, Office of the Public Advocate SA	2021-2024. Develops supports for people under guardianship of the Public Advocate to express and realise their life goals and to exercise choice and control. It also develops training resources for staff in mainstream agencies - with a focus on health services - to support service users to develop a My Life Plan document. Integrates supported decision-making principles with a resilience framework.	http://opa.sa.gov.au/article/view/88/living_my_life_project
South Australia	Supported Decision-Making for the Lifetime Support Authority	SA Office of the Public Advocate	2020. Policy and practice framework to implement supported decision making principles in the Lifetime Support Scheme, for service users with acquired brain injury. Uses the MyPlan process to promote a holistic, person-centred decision-making and goal-setting.	https://www.lifetimesupport.sa.gov.au/__data/assets/pdf_file/0004/286843/GA00049-Supported-Decision-Making-Project.pdf
South Australia	Supported Decision Making Project	SA Office of the Public Advocate	2010-2012. To identify opportunities, barriers, best practice and legislative reform for implementing supported decision-making in contexts of guardianship. The model provided a “non-statutory supported decision-making agreement”.	http://www.opa.sa.gov.au/resources/supported_decision_making Evaluation report: http://www.opa.sa.gov.au/files/batch1376447055_final_supported_decision_making_evaluation.pdf

State	Initiative	Leading organization	Brief description	Links and references
Victoria	TAC Supported Decision Making Program	La Trobe University, Transport Accident Commission (TAC) Victoria	2019. Training program for a small cohort of independence claims employees (support coordinators) to apply the La Trobe Support for Decision-making framework approach in their practice.	Douglas et al. (2020), Building capability to support client decision making: TAC Project No. T005, Living with Disability Research Centre, La Trobe University. (See also Appendix A to Final Report)
Victoria	Independent mental health advocates	Victoria Legal Aid	2015-2018. Training for clinicians about human-rights based, trauma informed, recovery oriented supported decision making.	Evaluation: https://researchrepository.rmit.edu.au/esploro/outputs/report/Evaluation-of-the-Independent-Mental-Health-Advocacy-Service-IMHA/9921863379901341 Weller, Penelope, Susan Alvarez-Vasquez, Matthew Dale, Nicholas Hill, Brendan Johnson, Jennifer Martin, Chris Maylea & Stuart Thomas, 'The need for independent advocacy for people subject to mental health community treatment orders', (2019), vol 66, *International Journal of Law and Psychiatry*, https://doi.org/10.1016/j.ijlp.2019.101452

State	Initiative	Leading organization	Brief description	Links and references
Victoria	OVAL Project	VALiD & Office of Public Advocate (Vic)	2015-2017. Decision making support by trained volunteers for people with cognitive disability in the planning and reviewing of their NDIS plans in the Barwon trial site.	https://www.publicadvocate.vic.gov.au/opa-s-work/research/144-research-item-on-frontpage (See also Appendix A to Final Report)
Victoria	Victorian SDM Pilot Project	Office of Public Advocate (Vic)	2013- 2015. pilot volunteer program to support socially isolated people with borderline to mild intellectual disabilities with their decision-making. Involving long-term and time-intensive engagement of volunteers.	Burgen, Brenda, 'Reflections on the Victorian Office of the Public Advocate supported decision-making pilot project', (2016), vol 3(2), *Research and Practice in Intellectual and Developmental Disabilities*, pp165-181
Victoria	Listening to People Rarely Heard	Deakin University and Scope Australia	2011. A supported decision-making framework and set of training and practice tools for people with Profound intellectual and multiple disability, and specifically communication difficulties. Co-design approach, and drawing on evidence base on communication, relational closeness, and narrative techniques.	https://www.scopeaust.org.au/research-projects/listening-rarely-heard/

State	Initiative	Leading organization	Brief description	Links and references
NSW	My Right to Decide - Supported Accommodation	NSW CID	2021-2022: A rights and wellbeing focused project working with people with intellectual and other disability who live in group homes and other supported accommodation. Individualised training to build skills and capacity to make decisions and speak up for people with intellectual disability and their supporters.	https://cid.org.au/event/my-right-to-decide-supported-decision-making/?utm_source=rss&utm_medium=rss&utm_campaign=my-right-to-decide-supported-decision-making
NSW	SDM and positive behaviour support	NSW CID, Flinders University, UNSW	2021. The project team will work with people with disability, their supports, service providers, and positive behaviour support practitioners to develop supported decision-making resources specifically for positive behaviour support. These resources will be available online for everyone involved to access.	https://www.unsw.edu.au/arts-design-architecture/our-research/research-centres-institutes/social-policy-research-centre/our-projects/supported-decision-making-for-people-subject-to-positive-behavior
NSW	NSW public guardian SDM	NSW Public Guardian, UNSW (evaluation)	2016-2017. Explored supported decision-making in relation to financial issues for people with cognitive impairment subject to financial management orders. Also provided training and established a community of practice more broadly for service providers.	Evaluation: https://apo.org.au/node/113076 (See also Appendix A to Final Report)

State	Initiative	Leading organization	Brief description	Links and references
Queensland		La Trobe University, Qld Public Trustee ('QPT')	2021.Aimed to train QPT staff to apply the QPT's Structured Decision-making framework and determine any change in practice.	Bigby, Chrisstine, Jacinta Douglas & Elizabeth Smith, *Considering human rights in decision making: Evaluation of the introduction of structured decision making framework in the Public Trustee Queensland*, Living with Disability Research Centre, La Trobe University, 2021 (See also Appendix A to Final Report)
Western Australia	DDWA supported decision making course	Developmental Disability WA	2021. Free online learning resource of two video modules which provides general information to guide the process of supporting decision making for a person with an intellectual disability.	https://ddwa.org.au/online-course-directory/supported-decision-making-course/
Western Australia	Supported Decision Making in Aged Care	Cognitive Decline Partnership Centre	2016-2017. Develop policy guidelines for aged care providers and a guide for people living with dementia, families and carers to promote supported decision making in aged care.	https://agedcare.royalcommission.gov.au/system/files/2020-06/RCD.9999.0033.0205.pdf
Multiple jurisdictions	Making Decisions Real	Inclusion Australia	2021-2024. Australia wide (online). Online workshops for people with intellectual disability and their decision supporters to learn about supported decision making. The workshops have been co-designed by people with intellectual disability	https://www.inclusionaustralia.org.au/registration-for-the-make-decisions-real-pilot-training-workshops-is-now-open/

State	Initiative	Leading organization	Brief description	Links and references
Multiple jurisdictions	Decision Making Possibilities	WAiS. Mamre, Sotica and Decision Agency	2020-2022. Perth & Brisbane. Designed to enhance decision making skills of people who mostly do not use speech to communicate. Supports include network facilitation, communication support, person-centred planning and education, and practice in supported decision-making.	https://mamre.org.au/decision-making-possibilities-project/
Multiple jurisdictions	My Life My Choices	CID NSW; SACID	2020-2021. New South Wales and South Australia. Co-designed program which facilitates workshops, information and resources to ensure people with intellectual disability understand their rights and the skills to share what is important to them in making decisions and when being supported with their decision making. Also provides training and resources for families, service providers and mainstream organisations about how to best support people with intellectual disability with their decision making.	https://sacid.org.au/wp-content/uploads/2021/07/SACID-Annual-Report-2020-2021.pdf (p.23)

State	Initiative	Leading organization	Brief description	Links and references
Multiple jurisdictions	Support for Decision-Making ARC Linkage	La Trobe University, University of Sydney, University of Melbourne, Qld University of Technology	2016-2020. Victoria, NSW, Qld. Developed training resources and workshops for supporters and decision makers and investigated the impact on their practices.	Bigby, Christine, Jacinta Douglas, Elizabeth Smith, Terry Carney, Shih-Ning Then, & Ilan Wiesel, '"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', (2021) *Disability and Rehabilitation*, 10.1080/09638288.2021.1964623 (See also Appendix A to Final Report)

Survey results on initiatives outside Australia yielded a smaller but more diverse set of initiatives, including:

- Programs delivering direct support for decision making (eg. support for will preparation in Birmingham, UK; Center for Public Representation and Nonotuck pilot in Massachusetts; the Bulgarian ‘Next Step’ program; and a Japanese decision support team facilitation program)
- Online resources for supporters (eg. Supported Decision Making Handbook For Parents and guide on decision making support for people using alternative communication, both from California; Webinar on ‘Assuring Better Communication for Deciding Together’ from Washington DC;
- SDM online resource libraries (US National Resource Center on Supported Decision Making and the American Civil Liberties Union’s Supported Decision Making Resource Library, both New York based)
- Research projects (eg Supported decision making experiences, approaches and preferences study from Belfast).

Appendix C

Perspectives of Supported Decision Making from Self Advocates, Supporters and Advocates

Christine Bigby, Craig Sinclair, Julia Duffy, Ilan Wiesel, Terry Carney, Shih-Ning Then and Jacinta Douglas.

1. Introduction and Aims

This study is about the perspectives of supported decision-making held by those involved in it. It forms part of a research project commissioned by the Disability Royal Commission that aimed to articulate the significance of supported decision-making to the lives of people with disability, and the principles, elements and ways of implementing best practice supported decision-making frameworks in Australia. The focus was people with cognitive disabilities who might be supported to make some or all decisions about their own lives, whether their need for support was lifelong, episodic, or increased significantly during adulthood or later life.

The study crossed usual boundaries, including both the aged care and disability sectors and the diversity of people with cognitive disability, their supporters and advocates involved in supported decision-making. It explored the perspectives of people with lived experience of cognitive disability, family members and representatives of advocacy organisations, service providers, and professionals about the benefits of supported decision-making, its elements and implementation issues.

2. Method

We used qualitative methods in the form of focus groups and interviews to collect data and grounded theory methods to analyse the data.[1] Ethical approval for the conduct of the research was given by the Human Ethics Committee of La Trobe University.

Participants were recruited through invitations posted on social media or circulated among the networks of the research team members and the extensive mailing list of the Living with Disability Research Centre, at La Trobe University. Table 1 summarises the way we categorised the 79 participants who took part in a focus group or individual interview. Participants with lived experience of cognitive disability were categorised as self-advocates and included people with intellectual disabilities, dementia and acquired brain injury and mental health issues. Advocates were categorised by the focus of their organisation. Importantly, however, the categorisations in Table 1 are only indicative as many participants had multiple identities that included more than one category. For example, some identified as advocates or professionals as well as family members, as well as having lived experience of cognitive disability.

Table 1. Summary of participants

	Focus Groups	Interviews	Total no. of people
Self-advocates	4	-	21
Family members or carers of people with cognitive disability	4	5	19
Advocates cross disability and aged care (generic)	-	3	3
Advocates-disability	3	1	9
Advocates-aged care	2	-	6
Advocates-carers	-	1	1
Service providers	2	2	6
Professionals	2	-	14
Total	17	12	79

The study was conducted during the COVID19 pandemic at a time when travel restrictions, health concerns and consequent staff shortages were taking a severe toll on the capacity of staff in all community and health services. Understandably, this impacted on recruitment of participants and meant that some groups were underrepresented, particularly minority groups such as those from First Nations or people from culturally and linguistically diverse backgrounds.

The fieldwork was conducted in November and December 2021 and February 2022 using digital platforms such as zoom or teams due to restrictions on travel and face to face contact as a result of the COVID 19 pandemic. The first author and two other members of the team conducted the fieldwork. Focus groups and interviews lasted between 30 to 90 minutes. A semi structured schedule of questions was used to guide discussion. Topics included: understandings of supported decision-making, its benefits and essential components; differences and similarities among disability or cultural groups and contexts of supported decision-making; preferred models of supported decision making; differences between formal and informal supporters; the types of standards and quality assurance strategies needed; safeguarding and regulation; barriers to implementing supported decision-making; where responsibility and funding should lie for supported decision-making, and differences between advocacy and supported decision-making. The schedule was adapted in focus groups with people who had lived experience of cognitive disability to include a focus on participants' experiences of being supported to make decisions.

All the focus groups and interviews were recorded digitally and transcribed verbatim with the exception of one where the recording failed. In this case notes were compiled immediately afterwards.

All the transcripts were read several times by two members of the team. The initial coding was by topic and captured eight key topics. Transcripts were then reread, summarised and inductively coded within each topic area to capture emergent categories and sub-categories. Constant comparative methods were used to develop and refine these codes across all transcripts and assist in collapsing codes into broader categories.[2] The transcripts and summaries were loaded into NVivo software and the code and query functions used for the processes of coding and refinement of codes. The first author led the analysis, which was progressively shared and refined with other team members. It was further refined in consultation with a focus group of members of the Supported Decision-Making Network.

3. Findings

The findings are organised under the main topic areas and the sub-categories of each of these: 1) supported decision-making – a contested concept, 2) furthering the exercise of rights - perceived value of supported decision-making, 3) diverse traditions of decision support, 4) elements of a supported Decision-making Framework, 5) supported decision-making and advocacy – supporting a decision or addressing issues, 6) implementing supported decision-making – obstacles, 7) facilitators of supported decision-making. Extracts from the transcripts provide evidence to support each sub-category.

3.1 Supported decision-making – a contested concept

Three different ways of understanding supported decision-making and its relationships to other forms of decision support were evident in the data. As one respondent said there is:

> a lack of clarity about difference between substitute decision-making and supported decision-making. A lack of consistency with supported Decision-making even in Australia between state legislation (advocate-aged care)

3.1.1 Supported decision-making as the binary opposite of substitute decision-making

Many saw supported decision-making as the binary opposite of substitute decision-making. From this perspective supported decision-making meant the person retained control of their decision, actively participated in making it and was supported to do so. Self-advocate participants talked about this perspective from their own supported decision-making experiences.

> Supported decision-making means you're in control of your decisions but still getting support while doing it. (self-advocate)

> Supported decision-making is about looking forward ...about how do you navigate your next step…(self-advocate)

Supported decision-making was distinguished from substitute decision-making by active participation in the process of decision-making, irrespective of whether an interpretation of the person's will and preferences was the centre of a decision made. This was very much a 'common-sense' or normative interpretation of supported decision-making, where support assisted the person to understand and explore information, options, and the implications of decisions and the person clearly made the decision themselves. Understood in this way supported decision-making had clear limits to whom or to which decisions it was applied. Respondents found it particularly difficult to apply this way of thinking about supported decision-making to people with more severe cognitive impairments, as even with support they would be unlikely to understand the choices or implications of most decisions.

> Some people will always need a substitute decision made – to pretend that a substitute is a supporter could lead to abuse (advocate-disability)

> For someone who has a profound cognitive disability – is the supporter ‘making substitute decisions in essence? I think they probably would be, in which case, we would need to recognise them as a substitute decision-maker, not as a supporter (advocate-generic)

> ...when do you need to take over when someone clearly has not got capacity at that point. This needs to be part of practice/program design (advocate-disability)

As the quotes illustrate, implicitly this perspective was underpinned by ideas about capacity. This meant supported decision-making would be limited to those who, with support could reach a notional capacity benchmark for making an informed decision. Where that benchmark was set and where the line around supported decision-making was drawn was however, by no means clear cut. It was thought to differ not only for each person but also for each decision a person might be involved in.

> …need to assess level of support they require to make that decision-. Depends on the nature and complexity of the decision. (advocate-carers)

> …someone living with dementia their cognition, and their other needs, will change over time, and so the supported decision-making process will necessarily change along with that, and it may well be, at the end, that supported decision-making is not possible…When is it not possible? Million dollar question – no clear answer. (advocate-aged care)

For people with increasing support needs, earlier supported decision-making practice was seen as leaving an important legacy of knowing the person and their preferences that could inform any future substitute decisions. As one of the advocates said:

> But even when you need to make decisions ‘for’ someone at that late stage, there has already been established the foundation of knowing that person’s decision-making preferences through having worked with them for a period of time. (advocate -generic)

3.1.2 Supported decision-making as part of a continuum of decision-making support

Rather than a dichotomy of supported or substitute decision-making, the most common way of understanding supported decision-making was as part of a continuum of decision-making support. From this perspective the role of supporters and type of support might intensify or change as support needs, or the type of decision changed. As respondents said,

> this is the continuum decision-making kind of argument, it’s just the most supported form of decision-making as opposed to the least. (advocate-generic)

> ...you might be able to make a decision about one thing, but not another, or maybe you can on that day but not another. You know, put it in a supportive environment where it's well explained to you, you can clearly articulate preferences but not if you're in a crowded busy room, or you're tired or unwell. (advocate-aged care)

There was a sense that little attention had been given to those with most severe cognitive impairments who did not use words or concepts to communicate but whose behaviour, actions or demeanour might be interpreted to demonstrate preferences. Respondents felt strongly that this group should not be excluded from the benefits of supported decision-making. This meant thinking differently about a simple dichotomy between supported and substitute decision-making and reaching a threshold of capacity.

> The hard one is profound disability, particularly where that is something that the person has been born with – I guess that ability to demonstrate preference, for instance, probably only comes through in a behavioural sense as opposed to verbalising decision-making preferences and I think that then becomes a really challenging process…. but there are always ways of eliciting a preference using alternative communication methods. Yes, sometimes those are and will always be indicative decisions using action or behaviour versus verbalisation… But that's not to say that there aren't other areas of decision-making that they can and clearly do indicate preference in (advocate-generic)

From this perspective, the continuum should include support that was neither supported nor substitute, but rather something different that occupied the space between the two. As many respondents explained eloquently a new concept was needed to capture clearly where supported decision-making sat on the continuum and what was expected of supporters.

> And it's almost like there does need to be another name for that space. It's not quite substitute, it's not supported. There's something else there, I don't know what you'd call it. (advocate-generic)
>
> To call it 100% support is a fantasy – prefers facilitated decision-making or representational decision-making. (family-disability)
>
> But bigger decisions – where he lives, managing phone, spending money, voting, decisions with a legal edge, might have to have something different than supported Decision-making. (family-disability)
>
> …maybe there needs to be another term there because it's not substitute decision-making in that sense of, "This person cannot make a decision and so someone else is just going to need to do it in this circumstance." And it's also not "Here is their decision because I understand [their preferences] that I'm just telling you what it is." There is something in the middle there where you are really trying to make a decision that's really honouring the person's participation and really trying to identify their wishes even when that's incredibly difficult, but acknowledging that there's a whole heap of interpretation going on there, so you can't be sure that that is what the person wants. (advocate-disability)

3.1.3 Supported decision-making as a principled approach to decision making

The third perspective understood supported decision-making as a principled approach to support that applied to all people and decisions irrespective of whether a person actively participated in making a decision or if it was made by a supporter based on interpretations of their will and preferences. From this perspective the principles of supported decision-making were embedded in any form of decision support. This meant that all substitute decision-making had to take account of the person's will and preferences.

> …so that supported decision-making is practised even when there is a guardian. (advocate-carer)

> …there should be an increasing legal requirement for people making substitute [or representative] decisions on a 'substitute judgment' basis… means that the representative makes decisions that accord with the preferences of the individual. They would still be substitute decisions, but they'd be made by people informed about what the preferences of the person are or were likely to be. (advocate-generic)

However, somewhat contrary to the sentiments in these extracts, most respondents identified the need to retain some form of substitute decision-making which could entail overriding a person's preferences in order to manage risks of harm to the self or others. In this respect risk of harm rather than capacity was perceived as the limiting factor to a supported decision-making principled approach to decision support.

> where there's genuinely not the best interests of the decision maker in mind, where there's toxic conflict between supporters…. when someone's in crisis. (service provider)

3.2 Furthering the exercise of rights - perceived value of supported decision-making

There was unanimous support for the concept of supported decision-making, and a sense that its benefits were self-evident, as one of the fundamental strategies for putting rights into practice.

> …if everyone's listening to me, then I'm much likely to be living the life that I want to live and be free of those abuses. (self-advocate)

Supported decision-making was seen to benefit people with cognitive disabilities in multiple different ways: by safeguarding, empowering, improving wellbeing, emphasising the importance of social connections and furthering social change. From a broader perspective supported decision-making done well was also seen as having the potential to save costs and improve the effectiveness of individual funding schemes such as the NDIS. Some notes of caution were raised about supported decision-making and the dangers of seeing it as a panacea for service system problems.

3.2.1 Safeguarding

Most commonly supported decision-making was identified as a strategy for ensuring the safety of people with disabilities and protecting them from abuse. Primarily this was because supported decision-making meant others, besides service providers would be involved in the lives of people with disabilities. This was seen not only to act as a deterrent to potential abusers but also to identify abuse much earlier if it did occur. As one respondent said, ‘harms occur behind closed doors’. In particular having more people involved in a person’s life was seen to reduce the vulnerable situation of people with more severe cognitive impairment who are unable to raise concerns themselves about what’s happening to them. In addition, the intention behind supported decision-making was seen to provide a set of principles to guide all support to a person, potentially improving its overall quality. Respondents said, for example:

> If supported decision-making is in place, then there’s theoretically an independent person or 2 or 3 people who assist a person in a process of decision-making - supported decision-making means that decisions are made in a way that respects rights, and a person’s voice is heard – and these things point to prevention of abuse. (advocate-generic)
>
> There’s an intentionality with supported decision-making and principles guiding practice – so when that’s happening, it’s a significant safeguard. (service provider)
>
> to get really good supported decision-making, they will need and have more people in their life, more people around them, whether that’s formally in a circle or a micro board, or whether it’s just an informal network. But by having those people, the more eyes there are on a person who’s got vulnerabilities, the safer they are, the less open to abuse and neglect. (family-disability).

3.2.2 Empowering and furthering wellbeing

Supported decision-making was perceived as furthering the empowerment and self-determination of people with cognitive disabilities in a range of different ways. These included: individuals experiencing greater exercise of choice and control; support to navigate complex systems; assistance to understand information and explore a broad range of options; increased opportunities to make decisions, and a greater likelihood that decisions would reflect their preferences. By having more opportunities to make decisions and have one’s choices respected supported decision-making was seen to further confidence, skills in self-advocacy and decision-making, and awareness of individual rights. Respondents said for example,

> if you have someone who is empowered to be involved and engaged in the decision-making about their own lives… the confidence and the competence that comes from that part I would think would be beneficial in terms of being able to…. raise the alert should they be in a situation where they themselves I guess have awareness that something doesn’t feel right… (advocate-generic)

There was also a sense from both self-advocates and family members that supported decision-making helped to improve the emotional wellbeing of people with cognitive disabilities by their having more control of their own lives, gaining a greater sense of self and experiencing less stress and frustration with their situation. Respondents said for example,

> There's a real difference with him – a smile, eye contact, when he gets what he wants. (family-disability)

> If you have the right supports, you can gain confidence – you do something with support such as catching a bus and you end up having the confidence to do it on your own. (self-advocate)

3.2.3 Saving costs and emphasising social connections

Some respondents thought that supported decision-making highlighted the significance of social connections to a good quality of life, and the corresponding dearth of connections beyond immediate services for many people with disabilities. By drawing attention to social connections, they thought supported decision-making acted as a catalyst for prioritising development of networks. They thought the emphasis of supported decision-making on social connections might potentially lead to the better use of funding and in the longer-term cost savings. For example, supported decision-making might help to focus planners' and funders' attention on the purchase of support that aimed to build a person's social network over time, rather than as often occurs at present, taking a short-term perspective such as paying for support to act as a companion for a person.

> Resources often used to getting someone out to a coffee shop – resource needs to be redirected into building networks and sustaining friendships. (family-disability)

> we are massively overinvesting in housecleaning and delivered takeaways meals …Because we have not understood well enough the distinctive needs and we are under-investing in capacity building sort of work…there are economies of savings – there's probably 20% savings in some of the practical supports sort of costs… (advocate-mental health)

3.2.4 Furthering social change

In various ways the value of supported decision-making was seen to be a powerful symbol with potential to influence social attitudes by reminding others about the rights and humanness of people with cognitive disabilities. It was also seen as illustrating the participation of people with cognitive disabilities not only in determining their own lives but also in civil society. As one disability advocate said, it was a way of 'translating values into things that are visible' and went on to explain how it was driving the involvement of people with cognitive disabilities in decision-making beyond the personal, by modelling respect for their views to others around them in families, services, and social systems.

> I do think that the symbolic value of it [supported decision-making] does matter to individuals because I think that symbolic value helps with stigma and it helps counter some social attitudinal problems. So I do think that even if it's just words and talking about it, I do think that has importance and value that does translate probably a fair way down the line, but I do think it matters, which is why I think the legislative reform matters not only for the practical side of things – giving tribunals and decision-makers and people alternative options, but I think it also says something – like as a statement about what our society thinks about people with intellectual disability or cognitive disability. (advocate-disability)

Perspectives of other respondents reflected this view, pointing to the negative effect when there was a low awareness supported decision-making.

> Without supported decision-making there have been times that supporters have treated me like a child, telling us what to do, not as an independent person. We can feel like we're looked down upon a bit. (self-advocate).
>
> Because aged care staff don't know people still have a right to be involved in decisions, they are unintentionally supporting elder abuse in some cases. (advocate-aged care)

3.2.5 Supported decision-making is not a panacea

Respondents also held some misgivings about inflated expectations about what supported decision-making might achieve in furthering the rights of people with disabilities. They pointed out repeatedly the dangers of single informal supporters and of endorsing informal substitute decision-making which had the potential to be as restrictive as formal guardianship and perhaps even more so if it lacked adequate formal oversight.

> …complicated though when the person abusing them is their supporter. (advocate- generic).
>
> Article12 CRPD is tricky – not only guardianship that can rob people of personhood, but quasi-informal guardianship by families and service providers. (advocate-disability)

Respondents also identified the potential for supported decision-making to be misinterpreted and for simplistic or misguided notions of autonomy to lead to neglect.

> And it's too easy for staff to say, "would you like to go out or would you like to stay home?" And Ned's sitting comfortably in the wheelchair, in his armchair watching some movie or some inane stuff on YouTube, and he's going to say, "Oh, I'll just stay here, thanks," because he doesn't like change and change is a bit harder for him and for other people. So, you can't present it like that. (family-disability)

These concerns flag the importance of there being more than one decision supporter, as well as some form of external monitoring or regulation of supported decision-making no matter the status of supporters.

3.3 Diverse traditions of decision support

As respondents talked from their own perspectives it was clear there were overarching differences between sectors in thinking about supported decision-making stemming both from different traditions of decision support and trajectories of need for decision support of the typical people each sector supports. The paradigm shift from capacity-based notions of decision-making to supported decision-making generated by the United Nations Convention on the Rights of Persons with Disabilities ('CRPD') remains incomplete in Australia and is occurring at differing rates in different sectors. Sectors with strong foundations in a medical model lag behind in shifting to a rights focus about decision-making. For example, the shift to a rights-based model occurred much earlier and is much stronger in the physical, sensory and intellectual disability sectors than in aged care, health, mental health, and acquired cognitive disability.

3.3.1 Decisions in the health or medical sectors

Supported decision-making is not well understood in healthcare or medical contexts, where issues of professional liability are often at the fore, driving risk averse perspectives. In this sector the focus tends to be on capacity rather than rights and distinct legislative provisions exist about what constitutes capacity to make informed decisions, and prescribing a hierarchy of substitute decision makers when a person is deemed not to have capacity. Notably, the health sector includes a wide cross section of people who require decision support for differing periods of time, long term, temporary or slowly increasing. One respondent who was a health professional reflected on perspectives in the health sector:

> I don't think there's enough understanding of the complexities around what supported decision-making actually is. ...certainly, the medical context, my personal take is medical professionals try to boil it down to a consent, a yes/no, a very simple "I need a yes/no answer." And often they look at a substitute decision maker who can give me the yes/no answer, rather than actually looking at the supportive process of getting multiple views, including the voice of the person who's going to be impacted by that decision…. I think there's definitely some work to be done. (professional)

3.3.2 Decisions involving people with mental health issues

The focus of decision support for people experiencing mental health issues has been two-fold. Respondents suggested that supported decision-making was incorporated into everyday practice of good professionals practising in mental health, such as NDIS recovery coaches. However, much of the focus in this sector has been on decision-making during episodic crises, where state based mental health legislation sets out conditions for substitute decision-making in circumstances where there is concern about safety or need for treatment. The episodic nature of mental illness has generated debates about tensions between long term or enduring will and immediate preferences. There is a growing rights perspective in this sector but legislative provisions are underpinned by questions of capacity and are similar to the generic health sector. People with mental health issues require decision support of an episodic nature during short term crisis situations and some require longer-term support as part of their ongoing day to day living.

For example, one respondent said,

> In mental health – supported decision-making is less developed. It gets to a certain point where someone is so unwell they are disenfranchised from their support network because of their complex behaviour. This means that the supported Decision-making framework falls apart. (service provider)

3.3.3 Decisions involving people with dementia and the aged care sector

Respondents thought that rights were not as strong in this sector although ideas that people with dementia have a right to have their views recognised and be consulted about care were gaining ground. Capacity, however, remains the primary point of reference in decision-making, and across the aged care sector respondents appeared to accept eventual loss of capacity and the need for substitute decision makers when this occurred.

> Lack of knowledge about supported decision-making in aged care generally although advocates might have some understanding. Aged care not really had a rights movement. (advocate-aged care).

People in this sector have an increasing need for support which occurs in the context of having had a long history of making one's own decisions.

3.3.4 Decisions involving people with intellectual disability

The intellectual disability sector was seen as having a longstanding rights perspective on decision making. Since 2006, the CRPD has driven debate about supported decision-making, and more so than in other sectors there has been a strong emphasis on the negative impact of removing rights that goes hand in hand with substitute decision-making.

This group has a quite different trajectory of support needs from other groups, having a lifelong need for support with decision-making. This means people with intellectual disabilities often have a limited history of decision-making without support which intensifies the need to build their experiences of decision-making and their capacity as one respondent said, 'from the get-go'. One respondent drew out the differences in supported decision-making with people with intellectual disabilities compared to those with dementia,

> …people with Downs Syndrome can get dementia – historically they wouldn't have had ability to express preferences but this is changing – but people with dementia without other disabilities have a history of making their own decisions…for people with intellectual disability there is an approach of building up capacity but in dementia there is declining capacity not trying to develop it for good life. (advocate-aged care)

3.4 Elements of a supported decision-making framework

A framework is akin to a skeleton, setting out the key elements that must be considered when thinking about something (a structure, a program, an analysis) that is to be developed. It is a guide to thinking about a phenomenon rather than a set of procedures or instructions. Frameworks may incorporate high level principles that should guide development and inform thinking about the other elements, they also include programs, legislative provisions and best practice. This section summarises respondents' views about the elements that should be included in a high level supported decision-making framework that encompasses all people with cognitive disabilities, all service sectors and jurisdictions across Australia. The eleven elements which are explained in more detail in the following sections were: 1) Universal principles, 2) Taking account of diversity, 3) Interrelationships with other systems, 4) Targeted programs that compensate for inequities, 5) Adherence to best practice models, 6) Community capacity building, 7) Oversight and monitoring, 8) Mechanisms for advance planning, 9) Co-leadership by people with disabilities, 10) Adequate funding, 11) Formal social connection building strategies.

3.4.1 Universal principles – Right to participation, decision-making and support

Despite the diversity of groups, contexts and decisions to which supported decision-making might apply, all respondents agreed there should be a universal set of principles,

> Principles need to be universal – not applicable to any one disability. (advocate-disability)

Although expressed in various ways, there was unanimous agreement that principles should rest on the rights of people with disabilities asserted in CRPD. As one respondent said,

> …there's some pretty obvious principles that could be drawn from human rights documents and the idea that the support for a person should maximise their participation in decision-making, in a way that doesn't lead to their harm. (advocate-generic)

Many were familiar with the National Decision-Making Principles proposed by the 2014 ALRC Report and thought these were still very relevant as foundational universal principles of supported decision-making. They are:

- the equal right of people with cognitive impairment to make decisions affecting their life and have those decisions respected (equal rights);
- access to support to make, communicate and participate in decisions that affect them (support);
- realisation of the 'will preferences and rights' in directing decision-making support;
- appropriate safeguards including against abuse and neglect.

Respondents commented that the ALRC principles were,

> very clear and aligned with supported decision-making. (service provider)

> very straightforward and that's really helpful. You don't want a lot of complicated stuff… they allow some human movement and flexibility as well, …in shades of grey, that you're not told that everybody can be supported and everyone can make their own decisions. And that's not always the case. (advocate-disability)

Several respondents did suggest the ALRC principles might benefit from updating to reflect changes since they were drafted. One concern was about the outdated language,

> …whenever I show them to staff, they're like, "Ew." They don't like the language and stuff …. since 2014, times moved on a little bit and they would benefit from a review, "Is this really the language they're after? Is it saying what we really want them to say?" (advocate-disability)

This respondent explained that use of the term 'persons' and 'assessing decision making ability' were seen as no longer reflecting contemporary attitudes or language. Another concern was that using rights in the combination 'will, preferences and rights' to guide decision support and substitute decision makers did not recognise the potential for different rights to be in conflict with one another.

> …they go through that series of possibilities, supported decision-making through to where there's substitute decision-making, and a person's well-known preferences should guide the substitute decision-maker. And where there's little to draw from their past, then the substitute decision-maker should act in a way that promotes the person's rights. And the only thing I would say is, the use of rights there is problematic, and not particularly instructive, because it doesn't actually help at all, because you can have competing rights to different things …just on that element, I would say there would need to be some work. (advocate-generic)

This respondent suggested rather than use 'rights' in the context of guidance to substitute decision makers, it would be preferable to follow the lead of the Victorian legislation which uses 'promote the personal and social well-being of the individual' as an alternative to rights. This respondent did recognise, however, that this term could be perceived simply as a more 'modern rendition of best interests' which might be out of step with a rights paradigm.

A further suggestion relevant to the substitute decision-making end of the continuum was to incorporate some of the recommendations made by the New South Wales Law Reform Commission's Review of the Guardianship Act, particularly around decision support with First Nations people and strategies to further the inclusion of people with cognitive disabilities in the processes of tribunals that appoint substitute decision makers.

> I also really like the New South Wales Law Reform Commission's Review of the Guardianship Act. It is all about just tinkering with it to make it stronger, but it's better on First Nation stuff. It's better on just some really basic procedural things within the tribunal as well that would make people's lives a bit easier around end of life and that kind of stuff. (advocate-disability)

3.4.2 Taking account of diversity

Respondents recognised the importance of embedding flexibility into a supported decision-making framework, to take account of the diverse contexts where supported decision-making would be practiced. This would ensure that principles, programs and best practice were translated and tailored to: specific subgroups of people with cognitive disability, decisions, sectors, decision contexts, jurisdictions, service systems, cultures, timeframes for implementing decisions, trajectories of support needs and potential risks or gravity of harm. Taking account of diversity would help to ensure both good practice and an acknowledgement that supported decision-making has to be embedded within other sectors or service systems rather than standing alone. Respondents said for example,

> Need generic frameworks legally – that allow for various forms of support to suit circumstances and needs. (family-disability)
>
> Could have a lighter version that covers more people OR maybe sharpen our focus on people most at risk – and others have universal systems. (advocate- disability)

Related to issues of diversity, many respondents were keen to ensure that supported decision-making was implemented in ways that gave people choices about how, by whom and under what conditions they would be supported. For example, one responded recalled,

> …someone saying they didn’t want to have a friend helping them. They wanted to go and see a professional for support because they wanted to keep that clear line about who did what and they probably still go to their friend about some kinds of decisions, but for supported decision-making as a proper thing, they wanted to pay for it, they wanted to go somewhere and talk to someone. And that was just that person and there would’ve been other people that had a completely different idea. (advocate-disability)

This not only spoke to the importance of choice but also to the need for continuing evolution of supported decision-making programs and practice, for which there was relatively little evidence about effectiveness.

> …whatever you’re doing we should agree to a set of principles ... because then that gives people the freedom to work out what type of relationship they want and then you can have some innovation there as well, like that guy who said he wanted a professional, well, maybe that’s in his plan that, he gets to go and employ a decision-making supporter to help him work through what he wants to do…Or maybe there are peer groups where people set up groups to help each other learn about different issues and then make decisions. It depends what you want them [decision supporter] to do. (advocate-disability)

This respondent went on to describe the diverse types of support roles and relationships that might need to be accommodated in a supported decision-making framework,

> ...it just depends on when the supporter is moving from just being a sounding board and helping someone think things through to where they're then maybe moving into a bit more of an advocacy type role where they're speaking on behalf of the person to get access to their personal information if they're interacting with an organisation. And then the next level is they're acting on behalf of the person to implement a decision. (advocate-disability)

3.4.3 Interrelationships with other systems

Respondents asserted that supported decision-making was inextricably intertwined with other service systems and should be embedded in both mainstream and specialist services used by people with cognitive disabilities, and in existing institutional frameworks such as Guardianship and Administration, Public Advocacy, and regulatory bodies such as the Aged Care Quality and Safety Commission and the NDIS Quality and Safeguards Commission.

> Supported decision-making needs to be embedded in 'the quality and safeguards, the practice standards,' and other evidence accepted by quality auditors (advocate-disability)

> Need a culture of supported decision-making embedded in each institutional process and policy (advocate-aged care)

Over time they hoped for culture changes that would mean good supported decision-making practice became integral to all support practice, no matter what the context, decision or need for support of the person involved. In turn this might reduce the need for dedicated supported decision-making programs:

> Agencies with responsibility for people with disabilities need: a good understanding of decision support; to have proficient practice, and to have a supporter available…the better all the service network, whatever those things are, at supporting decisions, then the less need there is for it [supported decision-making]. (advocate - disability)

3.4.4 Targeted programs to compensate for inequities

All respondents recognised the deep inequities of access to informal decision support among people with disabilities. The most disadvantaged were seen to be people without strong and resourceful family or informal networks - without any relationships outside service systems, and those with severe and profound cognitive disabilities for whom expression of preferences and participation was the most difficult. These were seen as priority groups for new formal supported decision-making programs that might include the appointment of continuing paid independent decision supporters and proactive building and maintenance of a circle of supporters. Many proposed that new supported decision-making programs be targeted to compensate for inequities in decision support rather than risk benefiting only those well placed to take advantage of programs.

> …because if you have a skilled family, you are greatly advantaged. (advocate-disability)

> if you don't have close relatives or don't really have much support, the government needs to provide it. (self-advocate)

> a cohort needs funding for independent advocate to assist major decisions – not just menu choice, but hard stuff – for isolated people without families. (advocate-disability)

As well as compensating for inequities, respondents wanted supported decision-making programs to be targeted at specific groups of people with disabilities, specific sectors or around specific types of decisions or risks.

> Would like to see formal systems available for people dealing with different government agencies, services and legal systems. (advocate-disability).

> Trying to come up with one size fits all won't work. (self-advocate)

> Policy doesn't need to be generic because you need the expertise of those who are more familiar with particular groups. (family-disability)

Program designs were seen to depend on the target group or context. Respondents commented on their experience of pilot or established programs rather than suggesting blueprints for new programs that might be needed (see the Appendix A and B of the Final Report for details about these). Thus, the programs mentioned were diverse including: drawing up decision support agreements; resourcing and monitoring informal supporters; finding and matching new supporters to people without informal supporters; appointing and supporting a decision supporter for specific sets of decisions; joint appointments of informal and formal supporters; creating or maintaining circles of supporters, and training and building capacity of supporters more generally. Many suggested that inclusion of funds to purchase supported decision-making in NDIS or aged care plans would not only provide access to support but would generate growth in specialist supported decision-making services.

3.4.5 Adherence to best practice models

Adherence to best practice decision support was seen to be a key element of a supported decision-making framework. Respondents thought models of best practice could guide support practice and help ensure its quality by setting out principles, processes, skills and conditions for good practice.

> We need key practice elements identified by researchers. (advocate-generic)
>
> Need a framework and process that people can follow. (advocate-disability)
>
> The planning process would need to include steps/questions that make the planners think about supported decision-making – what have you done to make sure you hear the person? Who's supporting them? …it would definitely help if we were able to use an supported decision-making framework. (service provider)

Some aspects of practice were seen as common to all groups and contexts and others as requiring context or group specific knowledge or skills. For example, knowledge of the service system context and skills in navigating systems were seen as prerequisites. As advocates said:

> A 'big ask' for an 'advocate' or supporter to get across all systems -guardianship, housing, child protection – but principles remain the same and the supporter needs to be working in the same framework. (advocate-disability)
>
> The type of support will be different across individuals, although similar in trying to promote autonomy. (advocate-carers)
>
> Need to use language that is inclusive and is about expressing will and preference. Actual strategies and tasks and activities may be very different depending on how the person expresses their will and preference. (service provider)

3.4.6 Supporters – principles

Various principles about supporters, their standing and relationship to the person they supported or service systems were proposed. These included,

- paid supporters should be independent of services and funders,
- standing should be accorded to informal supporters where necessary,
- ideally there should be more than one supporter,
- supporters should be chosen by the person they were supporting,
- supporters should have a trusting relationship with the person they support,
- supporters' roles should be clear.

That paid decision-making supporters should be independent of services and funders was seen as fundamental to avoiding real or perceived conflicts of interest. This was thought to be particularly important for people with cognitive disabilities living in supported accommodation (be it disability or aged care) who might receive all their support from one provider, and people using the NDIS system. As one advocate said,

> Supported decision-making needs to be independent because in the NDIS system, no one is independent, not the support coordinator, the NDIA, nor the service providers. Service providers can be good, but that's lucky rather than by design, so there is a need for an independent person. (advocate-generic)

According formal standing to informal supporters was seen to be important in facilitating their role vis a vis entities outside the immediate service of the person they supported as well as within that context. For example, formal standing could facilitate a supporter's access to information or the ability to represent the person in interactions with commercial or government entities involved in a decision, or to influence others involved in the person's life.

> …service providers will be much more willing to involve that person if they're part of a program, they're not just some random stranger. (advocate-generic)

One respondent talked about the advantages she had experienced as being formally recognised as a decision supporter in a healthcare context and suggested the benefits of such recognition in other aspects of a person's life.

> … if we're talking about decision making in houses or in people's lives apart from health, then it's that they might have a right to see key worker reports or the sort of internal documentation that families never see, or incident reports that involve the person concerned. … if you give people that title, then people kind of respect that title…I could imagine if I was given a title of Ned's supported decision maker, whether I was Ned's mother or his advocate or whatever role I had or his friend…then it would give me a kind of credibility to say to other people, "Well, look. This is how it's best to support Ned in decision making." I could then play a training role, if you like…it would give a credibility rather than oh, you know, yeah, she's just arguing about it, she's just Ned's mum, you know? (family-disability)

Whether or not formal recognition was necessary and the mechanisms for this were seen to depend on the particular context or decision being supported.

Many respondents expressed a preference for more than one supporter being involved in supported decision-making with a person. Ideally many thought a person should receive decision- making support from a network of paid and unpaid supporters around them.

> If you've got a collective, then you also have the scope… doing your interpretation…, 'Well, I'm just going to check with the other guys what they think you're saying there, because I've got an idea what I think you're saying there. But I want to see if they're picking up the same

> thing and interpreting what you're saying the same way', because that's a necessary thing…Part of the advantage of having a group of people around that person – rather, one individual – is, one individual, I think, runs the risk for themselves of not being reflective enough in their practice… I think if you're overly reliant on one person, then there's all sorts of risks in that. (family-disability)

> Multiple supporters can produce transparency and checks and balances. (advocate-generic)

> Safeguarding will be promoted in difficult or best guess cases if there is more than one supporter involved to triangulate opinions /interpretations. (advocate- disability)

> …because when you're interpreting will and preferences, you have your own lens, and someone else can interpret things differently – to suggest that there's an objective truth is unhelpful – need to wrestle with different interpretations. (service provider)

However, where multiple supporters were involved the importance of role clarity and collaboration among them were emphasised:

> You have to be very clear with others (eg., care team) what your role as a supporter is, and how you're going to work. It can be very difficult. (advocate- disability)

> People want all the different people who help them make decisions recognised…. have a key person who is adept at supporting a person to make decisions and understanding will and preference – and they oversee how others in the network operate with decision-making. (professional)

Related to concerns about role clarity and multiple issues, respondents also thought that a person should be able to choose their decision supporter/s and the roles they played and develop a trusting relationship with them if there was not already one.

3.4.7 Time – a prerequisite for good support

Respondents saw best practice decision support as skilled, complex and often intense, which above all else required time in order to be done well. Attention to the need for sufficient time to enable good supported decision-making practice was raised by almost all respondents irrespective of their constituency:

> to be given the time to do [supported decision-making]. (service provider)

> Three people in my house can't use an iPad or phone – so need to have worker who 'notices things in that person, notices little things that they enjoy…' or activities they do. Two of them have parents involved but they can't speak to let their parents know they're not being supported to make decisions. Sometimes you just need to observe, take the time. (self-advocate)

> Need to give people time to do supported decision-making – an investment in patience and skill. (advocate-generic)
>
> Takes time ultimately to provide supported decision-making to an individual. It is based on trust and relationship, so even if you have the skills and go into supported decision-making as a profession, with tools for communication support and getting to know the person it takes time. Structures in place in the different sectors need to allow for it. (service provider)
>
> it was extra time, and questioning me in all different ways to make sure I understood it. (self-advocate)

Emphasising the need for sufficient resources to allow supporters time for good decision support, one respondent suggested that not having enough time could be disastrous as it might mean a supporter could not engage with the person:

> So, the risk is that in trying to do supported decision-making in haste, or at arm's length, or shortcuts or whatever, there may certainly be cases where that's manageable, but certainly the clients we've dealt with, that would be a disaster. (advocate-disability)

3.4.8 Decision Support Practice Frameworks

The most commonly mentioned decision support practice frameworks were those based on the translation of research about decision making and support. These were the La Trobe Support for Decision Making Practice Framework, developed from research about people with intellectual disability or acquired brain injury, and the Spectrum model developed from research with people with dementia. It was telling perhaps that almost all of the key elements that respondents felt should be included in best practice frameworks for supported decision-making were included in both of these research-based frameworks. We summarise below the key elements described by respondents.

Knowing the person and tailoring communication.

Respondents saw knowing the person well as core to good support. This encompassed understanding how a person communicates, understands and processes information, and their family, social and service contexts.

> Clearly, you need to start with knowing the person with disability and getting to know how they communicate and express their will and preference. (professional)
>
> …long term as well as immediate preferences requires deep knowledge of the person so you can take a will as preferences position … Put yourself in their position – but not what they'd chose right now (eg., refusing a needle and treatment) but what's important to them in the longer term …Support to make decisions 'that are resonant and meaningful for them for the person they are, for their priorities, for their values.' (family-disability)

> …getting to know the person, getting to know their will and preference. Getting to understand the context that they live in. What their environment is. Who their important people are? All of those things are the background to really good, supported decision-making. … being able to understand how someone wants their choices presented to them…are they someone that is happy to have a conversation on the fly? Are they someone that wants to have a conversation, but then given a couple of days to think about it before they come back? Are they someone that needs that translated into some kind of collateral that they can hold on to, so that they can look at words or images in order to process? (service provider)

Expanding and exploring options.

Supporting a person to consider their preference about options for a decision was seen as much more complex than simply asking or giving them information. Rather it was seen as a proactive, and creative process whereby options were actively explored, and different strategies were used to elicit and understand a person's preferences.

> As supporters, we have an obligation to expand a person's decision-making context, environment so that we are not consigning someone to the same ideas, options and opportunities. (service provider)
>
> More than asking views but also supporting someone through the process, exploring options, considering constraints. (advocate-generic)
>
> …has to point out all the pros and cons, and what could happen to you, and can they sell from under you [sell property without consultation] and all that sort of thing. (self-advocate)

Ensuring a person had understood what might be possible or that as a supporter you had interpreted their response correctly was an important part of this process:

> …it was extra time and questioning me in all different ways to make sure I understood it, and open questions for me to come back to him to basically mirror what he said and understand it. (self-advocate)
>
> … then the person who's working as the decision supporter needs to have a way of acknowledging and reflecting back their understanding of that will and preference, so that then that can be supported to be conveyed in whatever circumstance that needs to occur. (professional)

Enabling risk

Directly addressing the risks that might be associated with a decision was seen as important, and if necessary, finding strategies to mitigate or enable risk:

> Any framework needs to address the issue of harm – ie What decisions is it appropriate to support and which not to support. (advocate-generic)

Listening and communication skills

There was unanimous agreement that all decision supporters needed good listening and communication skills. As one self-advocate said about the skills of a supporter she had valued, they:

> …had very good people skills and very good listening skills, which made a really big difference, and to have someone like that I think is really important, and I think you have to shop around for it. (self-advocate)

Objectivity and reflexivity

Awareness of their own potential to influence the person they supported, the ease with which they might be manipulated, and self-reflection were seen to be skills required by supporter.

> And the person who is providing the decision support needs to have some form of reflective behaviour that is - able to elicit any understandings of bias or where their views may, in fact, be getting in the way of conveying the person's will and preference. (professional)

> Supporters need to be trained and understand 'influence and subtle coercion,' and how to be objective and neutral. (advocate-generic)

Transparency

Being transparent about support processes and documenting the various steps used or options considered were seen as part of best practice, both in terms of accountability and reflexivity. Indeed, some respondents saw the processes of support as more important than outcomes.

> Transparency's important because I guess there's so many people involved in the lives of people with disability... who's giving her what advice and where that advice has come from (family-disability)

> …undertaking a process without an outcome in mind is a safeguard against undue influence. (service provider)

Tools such as checklists were seen as useful in assisting supporters to identify processes they had used.

> …this is the way we do things; we sit down around the table all together, all of the parties, go through this checklist, which is all from the person's perspective like 'did you want a second opinion? Have you had the opportunity to get a second opinion?' and then based on that checklist, you have like a 'this is how we're going to move forward', like a bit of an agreement, a bit of an action plan.' (family-disability)

3.4.9 Capacity building

Building understanding and knowledge about supported decision-making among the community in general and stakeholders more directly involved with people with disabilities was identified as a key element of a supported decision-making framework by all respondents. Indeed, there was significant optimism that a broad range of strategies, some with targeted audiences and others more generic could increase the skills of all potential supporters, assist people with disabilities to know their rights to support, maximise its effectiveness, raise community expectations about involvement of people with disabilities in decision-making and contribute to cultural change.

Need a policy structure to enable community capacity building. (family-disability)

One rationale for an emphasis on capacity building was the limited knowledge and misunderstandings about supported decision-making across sectors and the educative demands experienced by some pilot supported decision-making programs. As one respondent involved in a program said:

> we spend a lot of time educating service providers and others around what the rights are of the person, what decision support is, and what the requirements and how they might differ to what the service provider is requesting. …we often, we have a number of requests along those lines …just recently we had someone from NDIS refusing to do a review of a reviewable decision because they don’t believe the person has the capacity to provide that instruction…. I think a lot of education needs to take place…with service providers and the NDIS, and others. (advocate-disability)

Respondents saw the potential of capacity building to shift some supporters’ long held misconceptions about people’s capacity to participate in decision-making and equip them with strategies more aligned with supported decision-making principles.

> Families can be transformed by capacity building. (family-disability)

> Supporters need to be trained and understand influence and subtle coercion, and how to be objective and neutral. (advocate-generic)

For other supporters whose approach was already aligned with rights, capacity building would assist in giving them more insight into what they were doing and equip them with a language of support that could be shared with others.

> Parents and others want to know what it is, and formally, how they might do it – even if they’ve always done it intuitively. (professional)

A broad range of professionals likely to be in touch with people with cognitive disabilities was seen as benefitting from capacity building, including: lawyers, GPs, nurses, allied health workers as well as those who worked in the disability sector such as support coordinators or planners.

One respondent talked about the importance of building the capacity of medical staff to include issues of decision-making along with other key information when a person is diagnosed with dementia:

> On diagnoses, you are advised about: 1) your money, 2) health. Should be: 1) your family should be told about supported decision-making; 2) you should be told about ‘consent around what happens with your body, and 3) your money. Without capacity building, wives and partners have no way to support the person. (advocates-aged care)

Larger disability providers were also seen as important targets who were likely to influence in turn the expectations of direct support staff.

In parallel, respondents saw it important to build the decision-making skills and experiences of people with disabilities who had lifelong needs for support.

> We need education in decision-making, because if people haven’t made decisions in the past, they won’t understand options and risks. (advocate-generic)

For those still young this should start early both at home and at school,

> Supported decision-making needs to start early for people with ID – when they start school or earlier, so you build supported decision-making into their educational environment and develop help-seeking behaviours. (advocate-generic)

3.4.10 Oversight and monitoring

Oversight and monitoring the quality of supported decision-making were considered necessary elements of a supported decision-making framework. Many respondents were wary however, about the social acceptability and viability of regulating supported decision-making. They were also reluctant to consider the introduction of new agencies to fulfil regulatory functions around supported decision-making but rather thought such roles could be played by existing bodies with relevant expertise such as variously named state-based Offices of the Public Advocate.

> If we add regulation do we just add another body to create further systems and red tape and make things harder to navigate? (advocate-carers)

There was a strong sense that oversight and monitoring should differentiate between informal and formal decision supporters.

> Families shouldn’t be treated the same as workers. (advocate-disability)

While respondents saw it desirable to regulate formal decision supporters, they were concerned about the viability of doing this. In contrast they expressed doubts about the social acceptability of regulating informal supporters, the viability and the potentially negative consequences of doing so. Questions were raised about the reasonableness of scrutinising informal supporters and the impact this might have on their willingness to undertake this often onerous, unpaid emotional labour.

> Hard to monitor informal supporters or make people accountable in private relationships. There needs to be a space for informal decision makers who are doing the right thing to continue on without unnecessary intrusion. (service provider)

> The average family wouldn't want an 'inspector of decisions' – very hard to implement. (advocate-disability)

> …anything that creates a burden or obstacle to maintaining informal supports would be really problematic – a tricky balance. (advocate-generic)

> I don't think it's in any way realistic. I think people would find it hugely offensive to say, "You need to put in some report every six months to say". (advocate-disability)

In contrast to the strong majority view, several parents were less concerned about monitoring especially once they crossed from informal to a semi formal role such as being appointed as a person's primary decision supporter as part of a supported decision-making program. Indeed, they were used to requirements such as annual reporting currently required if they occupied a formal role such as a guardian or administrator.

Respondents were sceptical about the viability of regulation and generally had little confidence in its value without significant investment of resources in design and implementation. Regulation was seen as having unintended consequences and easily becoming burdensome and ineffective.

> …here is a risk that if a formal report is required, it becomes the only thing that gets done, rather than actually providing the services. (advocate-disability)

They drew attention to examples of ineffectiveness such as embedding statements about including people in decision-making in the Aged Care and NDIS standards in the absence of investment in developing capacity or monitoring. Attention was also drawn to failure to monitor adherence to the principles expected to inform the actions of nominees of NDIS participants. Some respondents thought that the focus should be on practice rather than on certifying competency against standards.

> …regulatory systems struggle, I think, to deal with these issues very well, so that difference between encouraging good practice as opposed to trying to regulate…No question, you need to have that power to get rid of the really bad ones… but the real issue is probably around generally our capacity to really track and look at quality improvement is very difficult to achieve in modern bureaucratic systems. (advocate-mental health)

> Just registration of provider with NDIS and quality audits are not enough…they have 'beautiful' policies. (advocate-disability)

> Aged Care Standards already endorse supported decision-making principles, but there is no funding investment. (advocate-aged care)

The most effective form of monitoring supported decision-making quality was seen to be having multiple eyes watching out for a person – people who could identify and raise concerns if necessary. This would likely result from community capacity building and good supported decision-making practice where more than one supporter was involved.

> Need to have 'a general community awareness and understanding of what supported decision-making should look like' in order to pick it up where the wrong thing is being done' and to rectify it through education. (service provider)

> Need community to be more aware of good supported decision-making so it can lead expectations. (advocate-disability)

> The team brings accountability for me – 'Team Adrian' – needs their support and inbuilt accountability because they know everything I do. (family-disability)

Risk based approach to quality oversight

The various strategies identified for assuring quality of supported decision-making resembled a risk-based approach moving from capacity building to monitoring or reporting against standards to formal scrutiny and approval of high-risk decisions. The rationale for this approach was the difficulty of monitoring day to day decision support and assumptions that some decisions were more significant or harmful than others to a person's quality of life

> …well, in terms of some reporting or some measures it would have to be proportional I suppose. It would have to be proportional for the risk or to the gravity of a decision …Potentially the gravity of harm that may come to a person in certain circumstances which might kick in for emergency powers to make decisions about a person's situation for example. (family-disability)

> Some families won't like recording the process – so have to spin it right – just for big decisions, or once a year, to make sure people are on track- but some people won't like it. (family-disability)

> Very hard to regulate day-to-day decision making as opposed to supported decision-making for bigger decisions relating to accommodation choices. (advocate-carers)

Inherent in this approach were assumptions about the feasibility of making objective judgements about risk or significance of a decision, which glosses over the often-subjective importance of a decision to an individual.

> Difficult to rank the size of a decision – but could look at consequences – the sector is very used to rating risk. If you're doing a risk assessment, then it is probably a situation of potential serious harm – and you would want that level of independent oversight. (service provider)

Capacity building

This was seen as the foundation for quality assurance that impacted on skills of supporters and awareness of community members about supported decision-making. Some respondents talked about their attempts to build capacity for supported decision-making with those around the people they supported in their services.

> Couldn't do more than bring in as supportive a system as possible – tried to promote and support good supported decision-making, ie, training families, workers, support coordinators, LACs [local area coordinators]. (service provider)

Respondents thought checklists and reflective practice derived from best practice models were useful tools for capacity building.

> …a checklist ensuring that each person that might give advice or is part of that, is almost like a declaration of upholding those rights of an individual within those situations that they've been taken into consideration, within a framework and very transparent to say, 'I advised this person this,' and took into account the different human rights, like a checklist to ensure that things aren't skipped and to give transparency over the parties involved and even maybe examples. (family-disability).

> But things like reflective practice, and an understanding of how supported decision-making is meant to work, then that is a significant safeguard. (service provider)

Practice standards and monitoring

Practice standards and some form of monitoring were seen as complementary to capacity building. Associated with standards should be provisions to remove supporters should they fail to meet standards.

> Need mandatory KPIs for supported decision-making and record them so they can be audited and a worker is then rewarded for taking the time to practise supported decision-making. (advocate-aged care)

> need to develop some good indicators for supported decision-making – some could be anecdotal – simple as 'what's the evidence they got choice of clothing?' Where has a person had 'opportunities to choose what food they eat, when they go to bed, when they don't go to bed, and stuff like that?' (family-disability)

> And the quality standards should have supported decision-making embedded and how you report against it – consumer experience reports need to ask about supported decision-making. (advocate-aged care)

> …but could have a code of conduct as a starting point. Problem is how to enforce it?

> Registration and then de-registration if there is a breach? (advocate-generic)

As these quotes suggest standards were perceived as insufficient unless accompanied by monitoring or reporting against them tailored to the role and context a supporter occupied. For example, if an informal supporter occupied a formal role such as a nominee, some form of low-level monitoring could be required, such as annual reporting or a declaration they had adhered to supported decision-making principles and practice.

> when it comes to a more formal status, perhaps a supported attorney role or a nominee correspondent, then in entering that legal agreement one would have to, as is currently the case, agree to certain behaviours and standards that you would uphold in doing so. And I suppose if those standards were breached, then someone, say a support worker, another citizen, another family member, could point out ways that it has been. And I suppose there would be almost a reactionary policing, for want of a better word, of a breach of that trusted role. (family-disability)

One respondent talked about the value of formalising informal supporters' roles, through mechanisms such as decision support agreements so that expectations could be made clear,

> I think that a formal tool can help contain a supporter, an overzealous supporter because you say what the supporter could do because without that specification, there can be some vagueness around what a supporter's allowed to do. (advocate-disability)

Many suggestions for monitoring involved recording decision support processes, using checklists, videoing interactions, or comparing supported decisions to earlier documented preferences of a person. Respondents talked about monitoring practices that were already in place, often remarking on how time consuming and labour intensive they were.

> We record the process, are clear about the steps – that is challenging. (advocate-disability)

> Paid supporters can record the process as part of their supervision… Could do written description, or a conversation (or supervision) of how you've gone through the framework, – gives a good step by step guide – don't have to do it for every decision. (family-disability)

> …currently looking at how to record decisions if making them 'with people' when they are substitute decisions. A fundamental process/tool is to record their wishes. (advocate-generic)

One respondent suggested that monitoring supported decision-making could be an additional task for community visitor schemes.

> Perhaps through community visitors – with the right scheme – an independent eye. (advocate-disability)

Another from the aged care sector suggested using information from internal quality control and feedback groups with residents as evidence for auditors about processes.

> Internally aged care homes are required to run their own consumer engagement and focus groups. Feedback from those is provided to assessors – so can demonstrate the residents have been consulted on a range of things from food to activities to quality of care. (advocate-aged care)

Several respondents gave examples of higher intensity monitoring than normally expected in respect of standards which would be difficult to scale up and which though they included supported decision-making extended to support practices more generally. Examples were an opportunity for people supported in a group home to have regular meetings with an independent person at which they could comment on their support, and supporters videoing their interactions around supported decision-making and sharing it with the support team.

> For the group home which she set up, they put in place a psychologist once a month, who didn't meet with parents or staff, who just met with residents so that they could have an independent voice. (professional)

> …one of my son's communication partners will sometimes do a phone video of their conversations and then we can look at it. (family-disability)

More stringent measures for high-risk decisions

For supported decisions that entailed high risks for a person, respondents thought there should be more formal documentation of processes that were scrutinised and approved by an independent oversight body.

> If there is only one supporter for a significant decision, you may need 'more strident safeguarding, or you'd want multiple perspectives in situations that involve serious risk …to the person or others. That way you could target resources at the more significant decisions – maybe the sale of property – 'some independence around decision-making that was happening there would be feasible and reasonable to expect'…. there could be a policy that would require something more significant than just documenting a regular process. (service provider)

> Maybe not a guardian in its current form 'but someone who looks at the decision proposed to be made and I guess tests the veracity of that decision in terms of what the person might choose for themselves… (advocate-generic)

> When making a 'best interpretation' of a person's will and preferences and the consequences are serious – eg., life-altering surgery – need 'some means to intervene beforehand' and 'have people record the reasoning for their interpretation of will and preferences…' (family-disability)

Roles of oversight and monitoring bodies

Respondents saw the necessity for one or more bodies to take responsibility for capacity building and oversight of standards. They were however reluctant to establish new bodies and saw these functions could be added to existing quasi government or non-government agencies which already had expertise in this type of work and public respect.

> I'm not imagining some new agency that gets set up to check on supporters of decision-makers; to administer it would be heavy-handed, and not a good use of resources. (advocate-generic)

> Probably the OPA [Office of the Public Advocate] because the community visitor program is close to it. Parents do have confidence in the OPA. (family-disability)

Dispute mediation

A final aspect of oversight and monitoring was the mediation of disputes between those involved in supporting a person with a disability to make decisions or between the person and supporters. Respondents described the success of various different approaches to mediation they had experienced. Examples were work undertaken an adult safeguarding unit in SA which took referrals from anyone who identified problems with the support being provided, and an elder care mediation service managed by Relationships Australia.

> You can make a report to the adult safeguarding unit and they can come and work with the carer to make them realise that the adult can make their own decisions with support. (advocate-generic)

> …could be quite distressing for both parties if the relationship is suddenly shaken up. So, we need to make sure that we address it in a way that supports everybody and doesn't create too much distress and provides those tools and skills. Then obviously if things are not working down the track, then there may need to be further intervention. If there's been a serious crime or something that needs to be investigated in its own right. But yeah, taking where possible and where appropriate, taking a supportive approach is probably the preferred option. (advocate-carers)

Opportunities for mediation with family members supporting an older person were perceived as helpful in avoiding conflict escalating to the stage where more formal processes such as an application for guardianship might be necessary,

> I do think there should be more mediation particularly for older people…in guardianship, a lot of time gets wasted on the fact that you're really dealing with the emotional state of the family members involved…So I think it would be nice to have a process of discussion and mediation with very skilled people before you got to guardianship. (advocate-disability)

3.4.11 Mechanisms for advance planning

Respondents from across the aged care, disability and mental health sectors all saw the value of mechanisms to enable advance planning for decisions that would need to be made in the future and which enabled a person to express their preferences ahead of that time. The situations where such advance planning might be relevant varied across sectors. Most commonly mentioned were various types of advance care directives that expressed a person's values, specific instructions or nominated a future substitute decision maker about issues of end-of-life care or medical treatment. Respondents suggested these were increasingly becoming a requirement of aged care services with benefits both for the individual but also in reducing risk for service providers.

> Need to get end of life things done long before dementia comes in… have to choose the right people. (advocate-aged care).

However, planning for decision-making about future care was not seen to be without problems. In relation to older people, honouring advance care directives was seen as challenging and often as one of many factors substitute decisions makers might weigh up. The issues were summed up in one focus group discussion.

> So, if you're someone whose made an Advance Care Directive prior to diagnosis for dementia, there's one line of thinking that suggests that should be honoured regardless of any changes that you might experience if you have cognitive impairment or dementia…Then there's another whole line of debate that argues, "Well no, dementia is a transformational experience and that any changes that occur, in that experience, need to be respected, and any change in wishes accordingly, including in relation to health needs, also need to be respected. So again, getting back to the earlier point, that may not be perceived as being in someone's best interest, but it still has to be listened to and respected…There is a middle line here, and it's actually what many people, supporting people with dementia, do anyway which is balance. Knowledge of previous wishes, whether documented or otherwise, or just verbalised, and current wishes or preferences if they're expressed and even if they've changed. (advocate-aged care)

Several respondents also expressed concern that tools such as values directives, which were designed to inform future decisions were open to abuse as they were not always completed by the person themselves. As one respondent said in the context of the current Victorian legislation:

> …there's a different form for someone who's not seen to have decision-making capacity, and that's the values and preferences form, and that's a completely separate form that the person doesn't have input in, it's filled out by someone else on their behalf. (advocate-aged care)

As with many other elements of a supported decision-making framework, the need for education and capacity building was seen as a critical element in the effective use of mechanisms that sought to inform future decision-making:

> people get appointed as substitute decision makers under Advance Care Directives, and people just think it's an opportunity to make decisions for a person as opposed to with the person. … [we are developing] education tools in relation to Advance Care Directives focusing on substitute decision makers because we want them to be educated and trained in supporting people to make their own decisions for as long as possible, or if they have to make them for them that they focus on the person's wishes and that objectivity… it's an education piece really…if there's no guardianship formal order in place there's no one to account to…it's education and education. (advocate-generic)

Several respondents raised the potential value of advance planning for change of a primary decision supporter for a person with intellectual disabilities in the future. As one family member said, this could avoid unnecessary formal processes.

> If you have recognised/appointed role of a supported decision maker then when parent dies, it is also recognised that someone needs to step into the role – maybe have a list of default decision makers – like the 'person responsible' hierarchy – don't want to have to go to VCAT every time – only if someone challenges the hierarchy. (family-disability)

Appointment of a future primary decision supporter would facilitate the broader issue raised by several respondents about the future care of a person with intellectual disability when their primary carer died. Rather than perhaps locking a person into rigid plans for care and accommodation for some time in the future, appointment of future decision supporters could mean greater flexibility and opportunity for greater involvement of the person themselves at the time decisions had to be made.

3.4.12 Co leadership by people with cognitive disabilities

Several respondents raised the importance of including people with cognitive disabilities themselves in consultation and design processes for supported decision-making programs. Their absence from law reform processes and debate about supported decision-making was seen as one of the reasons for the slow progress of reform. Putting forward the position that an element of a supported decision-making framework should be the inclusion of people with people with cognitive disabilities in leadership of supported decision-making and program design one disability advocate explained:

> Yeah. I think that people with disability really do need to genuinely be part of the process and I think there should be some requirements even about employing people because again, it's a cultural change for the organisation itself. And I think part of the reason why we don't have legislative change is because none of the people who are involved in decision-making are people with disability or kind of any skin in the game. We might have someone who happens to have a family member, but it's not integral to the decision-making process. So, I think that just entire absence of experience is problematic, so I think the presence of people in genuine co-design or genuine consultation should be built in somehow. (advocate-disability)

3.4.13 Adequate funding

Adequate funding to resource all element of a supported decision-making framework, in particular: best practice; capacity building; oversight and monitoring, and building social networks were consistently raised by respondents. Some pointed to the potential of existing agencies both government and non-government involved in supported decision-making but also the limited resources available to further this work. As already discussed in other sections respondents were wary of introducing programs, standards or monitoring of these without sufficient resources.

3.4.14 Formal social connection building strategies

As already flagged, respondents consistently identified the inequities experienced in supported decision-making initiatives by people who did not already have strong and resourceful family or other social connections outside of service systems. Yet as several remarked it was this group whose perspectives were seldom heard.

> We're interested in that person who is really super-quiet and is no problem to anybody, because maybe that person doesn't have any family, and has needs that are just being ignored…. (advocate-disability)

Although the significance of building social connections for those without them was raised, and overarching approaches were identified, there was a sense that there was very little real evidence about successful strategies or costs of this type of work. Initiatives that were identified were those of family based organisations and tended to rely on a person already having a core supporter around whom a network could be generated.

> Need more work on how to find people to be supporters. (professional)
>
> You can have a circle of friends…It has to commence with the family or someone who's extremely involved and fond of the individual. Paid staff cannot play that role. It is important for Dave he knows the difference between paid staff and friends…But a paid support worker with a dedicated role could absolutely help build a circle of support – but not be part of it. (family-disability)
>
> Have to have a core key person that will then build a network around them and maintain the network – in the long term doesn't have to be expensive…built around facilitator of networks around a person – doing a few hours a month. Takes longer to get them up and running but once established, not a lot of hours. (family-disability)

Whether formally constituted micro boards were one mechanism for building networks would be useful for those without networks was suggested but the requirement for a minimum number of members was seen as an obstacle.

> …it certainly takes some intentionality from the people that commit, for sure, which is potentially where the micro board model has a bit more stickiness to it, because it creates a legal entity that requires a formal decision if you're going to dissolve it. If you get less than six people or five people whichever State you're in, then you don't have enough members to be an incorporated association, so you have to wind up. That's one of the safeguards for a person in the long haul, if it's a legal entity, it doesn't need to be particularly onerous in terms of expectations of people, to keep it going is a legal entity. But it means that there's that commitment to keep this thing alive. (family-disability)

3.5 Supported decision-making and advocacy – supporting a decision or addressing issues

Several respondents suggested a Venn diagram could illustrate the overlapping and distinctive elements of supported decision-making and advocacy. The distinction between the two was summed up by a self-advocate,

> Supported decision-making is when I ask someone to help me make a decision - Advocacy is someone representing me. (self-advocate)

Independence from service systems and skills such as listening to the person, ensuring awareness of options and making information understandable were seen as common to both advocacy and supported decision-making. However, some respondents warned of generalising, pointing to differences in advocacy, suggesting that some types were more aligned with supported decision-making than others.

> If you're an advocacy organisation that primarily stands in front of the person and speaks on their behalf, [that's] not very aligned with supported decision-making. But if advocacy model is standing beside the person or behind them, then very aligned. (service provider)

Reflecting that advocacy stands in front of people, one of the self-advocates saw supported decision-making as more empowering than advocacy which from their perspective could be paternalistic:

> [supported decision-making] helps people to be able to tell the world what they want …advocacy is literally speaking for someone when they can't speak for themselves, whereas supported decision-making is enabling their voice to be first, front and centre of the conversation…it fosters confidence and self-belief, whereas advocacy is something I consider to be quite paternalistic, you know? As well-intended as it is. (self-advocate)

While those acting as advocates might support decision-making it was not seen as core to their work, and they were unlikely to have time to build the relationships necessary for good decision support or to develop a person's own confidence and skills for decision-making. Similarly, advocacy could be part of decision support but was not a central role of decision supporters.

A key difference was seen as when a decision was made. Advocates' involvements in decisions were more likely after decisions had been made by the person themselves or by others at a time when the focus was on implementing or challenging it.

> A lot of advocacy is also trying to help the person to self-advocate, but with advocacy people know the decision and often make the decision. They just want assistance in getting their way. (advocate-carers)

Advocacy was more likely to occur at a time of crisis and only involve a short-term relationship with the person whereas decision support often required a longer-term relationship. Some respondents thought advocacy required more knowledge of service systems than supported decision-making, while in contrast knowledge of the person was core to supported decision-making.

> …decision support is about the process of making decisions, and advocacy is about addressing issues and taking action, but beyond that, I think they're very closely related. …I think decision support is more about focussing on the person and where they're coming from, and what they want, and advocacy is more about how we get the system to work with what we need for the person'. '…in our mind, advocacy is pretty much issue specific – so domain knowledge is very useful – to resolve an issue. supported decision-making is more client focused on what you need to know about the person and what they prefer. The need is ongoing. (advocate-disability)

3.6 Implementing supported decision-making – obstacles

Many of the obstacles to implementing supported decision-making identified by respondents were associated with elements of a supported decision-making framework they identified but which they considered would be difficult to create, including: adequate funding, acceptability and common understanding of supported decision-making; effective monitoring and insufficient evidence for building social networks.

3.6.1 Formative state of knowledge and variable commitment to supported decision-making

Despite debate among advocates, academics and the disability sector over the last ten years, and various pilot supported decision-making programs, respondents considered uncertainty about the meaning and implications of supported decision-making would impede its implementation. In their view supported decision-making was not widely understood or embraced across sectors and knowledge was uneven between sectors.

> …there's a part of the disability sector that uses the terms, and then the vast majority of people with disability themselves, and the providers and the NDIA and everybody else, this is all foreign to them. (advocate-disability)

> ...older people’s human rights around decision-making get dismissed much more quickly than in the disability sector. (advocate-generic)

The patchiness of knowledge and embracing of supported decision-making across sectors compounded difficulties of implementing a national, cross sector, cross State and Territory approach to supported decision-making associated with Commonwealth / State / Territory jurisdictional arrangements.

> Need to look at aligning regulation across care systems while also acknowledging the need for some difference…. Very hard to have oversight across different sectors re abuse and neglect because rules and reporting are different, state and federal etc, different restrictive practices regimes. (advocate- carer)

Even in the disability sector, where supported decision-making had gained most exposure, respondents raised questions about the commitment of service providers to supported decision-making and their willingness to promote it. The reluctance to embrace supported decision-making was seen to stem from the potentially conflicted position of service providers in respect of decisions made by the people they supported or when a person they supported and family members held differing opinions.

> ...if an adult is surrounded by providers and others who have a vested interested in keeping them within their clutches then they won’t be encouraged to do supported decision-making – vicious cycle of vulnerability. (advocacy-disability)

> Service providers can be reluctant to challenge family where family are undermining the person. (advocate-disability)

Related to this were concerns that some services providers might adopt a minimalist or ‘lite’ approach to supported decision-making which might satisfy standards but would fail to have any substantive change in the way people were supported to exercise their rights.

> There is supported decision-making ‘lite’ where workers try and give simple choices – Weetabix or porridge but not enough…Providers are very traditional – but they can tick boxes for quality audits re pseudo choice –eg., menu and day program …But providers don’t seem to really sit down with the person and work out their choices. (advocate-disability)

In terms of knowledge, respondents drew attention to the critical role that support networks around a person played in supported decision-making. For some people there would be a need to build and nurture networks from a very low base, but respondents perceived there was very little evidence about how this could be done for people without strong family support or about the costs involved. While respondents pointed to family based organisations which had developed strategies to build circles of support and micro boards, drawing on international work from Canada, no parallel work was identified for those without family members. As respondents said,

> We don’t yet know how to build informal networks. (advocate-mental health)

> Natural relationships are the best, keep people safest – need paid support though to build those relationships – long-lasting relationships – NDIS is all about inclusion. (professional)

3.6.2 Scale of costs and capacity

Adequate funding for supported decision-making programs and capacity building were seen as key elements of any supported decision-making framework. The costs of implementing effective supported decision-making, particularly for those who are isolated, have high and complex needs or without informal support were perceived as high and potentially an impediment to the development of supported decision-making.

> But it won't suit the NDIA if those recommendations are expensive to the NDIS, if it requires additional funding. (advocate-disability)

Many respondents reflected on the underfunding and consequent overloading of the current infrastructure such as Offices of Public Advocates (OPA) or Guardians, which though well placed to further supported decision-making systems could only do so with additional funding.

> Systems such as public guardians are inadequately funded. Guardianship processes can be improved, but basically the architecture is pretty reasonable. (advocate-mental health)

> OPA caseloads are too big, so they don't have the time. (advocate-generic)

> My view is that with supported decision-making the OPA is 'in crisis'. They are unable to address guardianship requests in a timely way, there is a long wait for guardians, they are well under-resourced. As an advocacy service we might look to the OPA to better understand decision support but 'they're struggling to implement the law really'…There is a risk in trying to do supported decision-making in haste – could be a disaster for some clients. (advocate-disability)

3.6.3 Following through on rights and enabling risks

Supported decision-making, as a rights based approach to decision support challenges individual supporters and service systems more generally in terms of the risks it poses. Supported decision-making means discarding the notion of 'best interests' and enabling people to experience the dignity of risk. Potential impediments to implementing supported decision-making were seen as the risk appetites of governments. Respondents remarked on what they saw as an increasing risk averse position taken in the aged care and disability sectors.

> …it comes down to that risk aversion, "We don't want to get ourselves into trouble, we need to do whatever we can to make sure that this person stays safe," but then in doing so you're not giving that person the dignity of risk to do something, to make a decision that might not really be in their best interest, but it's what they want to do, like going outside unattended, you know….I mean the locked door thing, that comes up so often, "We lock the door because if they go out into the garden they might trip and fall and then they'll end up in hospital," "Well, they're miserable stuck inside and not being able to go out and sit in the garden." (advocate-aged care)

> Challenges with risk – especially for statutory substitute decision maker – pendulum swings in terms of public/political tolerances and with the Anne Marie Smith case tolerance for allowing risk has reduced. (advocate-generic)

They also warned of the dangers of allowing risk to dominate the design of supported decision-making, as the majority of situations were unlikely to revolve around these issues.

> Don't get stuck at the pointy end of high risk because you 'lose sight of the fact that like 95 per cent of decision-making may not sit in that space'. The culture needs to be enriching, not about containing or minimising risk…. You need to have systems to protect people from the unscrupulous supporter – but the system needs to be designed with the 95 per cent in mind – and have safety nets in place for the minority. (service provider)

In terms of the practice of individual decision supporters, respondents saw that furthering an individual's long-term wellbeing as well as their decision-making rights were subtle and skilled tasks, which at times might mean overriding immediate preferences and adopting a best interests approach. For example, Citizen Advocacy programs which aim to build long term mentor/mentee relationships for people with disabilities to support a good life, were clear that a mentor might override preferences and act in the best interests of a person to further their long term wellbeing.

> …it's about protection. And that's why the person's best interest is such a priority …. Have seen systems guided by 'expressed wish' and person can get themselves into even more damaging situation. So expressed wish is not our priority. (advocate-disability)

Similar sentiments were expressed by respondent about supporters in other decision-making contexts such as aged care where a person's preferences might change as support needs increased.

> And then there's a balance between what the perceived preference is now with the risk and the best interests that has to be weighed up too. So, it feels like supporters, in this field, don't want to give up the best interest element of decision support. (advocate-aged care)

As well as competing priorities about rights, wellbeing and safety, respondents also noted tensions in the current design of the NDIS as impediments to supported decision-making. The primary issues in relation to the NDIS were seen as the absence of a formal supported decision-making scheme for participants, any capacity building or oversight of nominees, or monitoring by NDIS planning or Local Area Coordinator ('LAC') staff, about the quality of informal decision support for participants. These issues were noted as having been the focus of a recent issues paper and consultation by the NDIA, which at the time of writing was being analysed.

As well as these broad issues, several more nuanced aspects of the NDIS design were raised which were thought to pose potential impediments to the implementation of supported decision-making. One of these was the requirement for NDIS participants to enter into formal contracts with service providers and the legal frameworks that prevented some people with cognitive impairments from doing so and drove a push for appointment of substitute decision makers.

> …competing forces at play, but we see the human rights developments that are increasing the call for supported decision-making in opposition to substitute. But then, we have service developments down into disability spaces, they are increasingly seeking decision-making authority, which led towards the substitute decision-making, which is problematic. (advocate-generic)

A second NDIS design issue was the process driven nature of the planning system and the time constraints imposed on the LAC role.

> NDIS doesn't really allow LACs to do supported decision-making because we are required to follow a sequence of events in a planning process that isn't sympathetic to complex experience…supported decision-making requires a long time to establish trust and rapport and the NDIA doesn't allow for that time…. They have done a 'time motion study' and estimate planning takes 4 to 6 hours – this doesn't allow for people with nuanced communication needs. (service provider)

Related to NDIS planning process was the relationships between those who may be involved in planning processes for a participant, who may include a formal nominee as well as other supporters.

> Needs to be a change in the planning process and more clarity about nominees. There needs to be a clear distinction between people involved in the planning process with authority to make decisions, and people who are supporting decision-making. This difference is not clear at the moment. (service provider)

A further tension raised that might impede supported decision-making was the juxtaposition of the rights of people with cognitive impairment with those of their carers which are recognised in legislation and would need to be taken into account as part of supported decision-making

> Need to understand that carers are there providing support and that 'people don't exist in a vacuum'. Carer Recognition act – states the rights of carers. Not enforceable but requires agencies to consider carers in development of supports. (advocate-carers)

3.6.4 Evidence gap about alternative and more collective perspectives about decision making

Many respondents raised questions about the applicability of supported decision-making to First Nations people with disabilities, referring to the community based and collective approach to decision making by indigenous cultures. One respondent explained this approach in detail which we have quoted at some length given the absence of documented accounts, evaluations or research evidence about this approach.

> we see it very much as our community is a collective community. Supported decision-making for a person who has a disability or doesn't have a disability is often the same. It's always a group consensus about what can and can't be done particularly in more rural, regional and remote communities…. And because we have a very well-built understanding of our

> governance structure and our authority structures, we know who needs to be part of the decision-making process. We have been doing circles of support long before it became known as circles of support. … And literally we do sit and decide who is going to make the decision and who needs to be involved in that decision-making process. And it doesn't mean that we're taking away the autonomy of the individual. The individual is still centred but the decision is collectively made about what's best for that person. And literally it is our way of doing the circle of support whether you have a disability or not… We hear what they want to – we hear what they say. We know what they mean through either their behaviour, their words and then we'll sit down and have a discussion about what's the best way to support that individual to do what they need to be able to do.
>
> For us, we would say in the framework it's codesigning with the person if we're going to use white person language. But that's the outcome of supported decision-making. The principle is to get the individual to have a sense of agency about their own life and the principle is based on belonging. It has to – every time we've seen change in an Aboriginal person with a disability, it's because they belong. That is the principle. That is unwavering. That gives the person a sense of individual agency because they know there's a level of trust to be supported as people that make decisions. That's the most profound thing if that makes sense. The second is understanding that cultural safety. Out of that sense of trust comes cultural safety. I feel safe with you. I feel safe with this organisation because the organisation has changed its systems and its method of working by having cultural safety. (service provider)

Some confusion, however, was evident between the community or collective approach to decision-making preferred by First Nations people and a supported decision-making approach that relied on an informal or formal group of supporters which retains a focus on the individual.

> Need to recognise collectivist decision-making – eg., micro boards, but also Aboriginal and Torres Strait Islander and CALD communities. (professional)

3.7 Facilitators of supported decision-making

Far fewer facilitators of supported decision-making were raised, than impediments to the process of supported decision-making. However, several important facilitators were identified. First of these was the very considerable, though under resourced infrastructure around advocacy and decision support across Australia in the variously named Offices of Public Advocates and Guardians. Added to this was the shift to individualised programs in disability and aged care which meant relatively simple mechanisms were already in place to allocate funding for a formal paid decision supporter to individuals which could then be purchased as part of a package from established providers.

> Need to include supported decision-making in NDIS plan so that adults can purchase support.…Could also include funding in aged care packages. (advocate-generic)
>
> Could come from independent advocacy system since that is already set up – need to be independent, like an advocate is. (advocate-disability)

4. Discussion

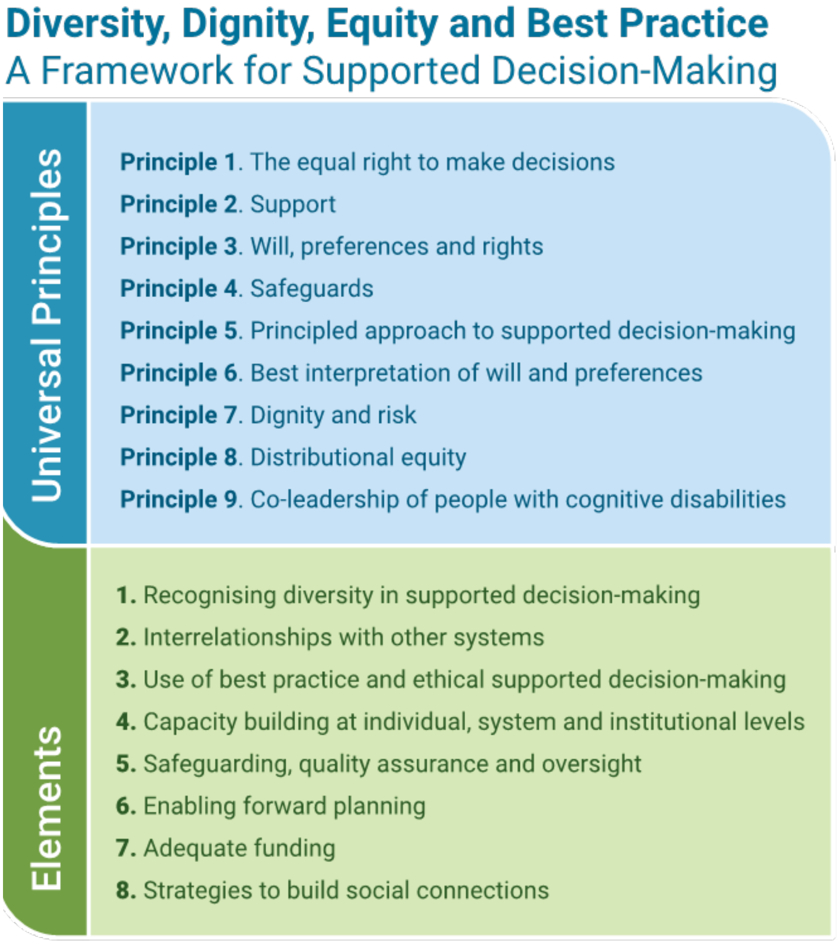
The findings from this study capture the perspectives about supported decision-making from a broad range of people with lived experience of cognitive disability, and those who interact with this group as supporters, advocates and service providers. They were experienced and knowledgeable respondents; speaking from their own experiences and broader, sometimes significant, knowledge of the literature about supported decision-making.

The perspectives of participants in the study demonstrate the diversity of contexts, support, supporters and decisions encompassed by the single concept of supported decision-making. They point to differing proportions of their life course a person might need supported decision making and the differing points in the life course where the need arises. Despite this diversity, there were few divergent views between different groups of participants. Rather there was a remarkable consensus about some issues and many overarching similarities in their perspectives. These included, for example:

- the significance of supported decision-making in furthering rights and wellbeing of people with cognitive disabilities;
- the key elements of practice such as the importance of relationships and knowing the person and taking a reflective approach;
- uncertainty about where the boundaries might be between supported and substitute decision-making;
- the ambiguities of including people with more severe cognitive disabilities under the umbrella of supported decision-making yet a desire to do so;
- the dilemmas for supporters of respecting the dignity of risk;
- the recognition that much supported decision making happens informally in people's day-to-day lives;
- the need for comprehensive culture change and capacity building to embed supported decision across service systems, institutions and professionals' practice;
- the need for continued innovation of programs, practices and policies about supported decision-making that demonstrate diverse ways of applying a set of universal principles and avoiding prescriptive models at this stage of its development, and
- the inequities of access to supported decision making among people with cognitive disabilities and absence for some people of meaningful social connections beyond paid staff.

Some of the findings align with existing knowledge and much debated issues in the literature, such as the differing pace sectors have taken in adopting supported decision making, the conundrums of including all people with cognitive disability in supported decision-making and dilemmas presented by competing the rights of autonomy and safety. Other findings add new knowledge to the literature particularly about the perceived benefits of supported decision-making, its role in social change and its difference from advocacy. Perhaps most importantly, the study adds new knowledge about the principles and essential elements of a framework for supported decision-making and the potential obstacles to be addressed for success of ambitious and comprehensive reforms.

This study formed the basis of the final stage of the project which synthesised its findings with those from the literature review,[3] a survey of work in progress[4] and consultations with an advisory group. During this process, we distinguished between principles of a framework, that inform all aspects of supported decision-making, and elements that guide development and act as design imperatives for operationalising principles and the development of supported decision-making law, policy, and programs. We recognised that three of the fourteen essential elements of a framework identified in this study (right to participation, decision making and support; targeted programs to compensate for inequities and co-leadership by people with cognitive disabilities) were more akin to principles than elements. We also collapsed four elements (supporters-principles; time – a prerequisite for good support; decision support practice frameworks; and adherence to best practice models) together as they all relate to best practice and ethical supported decision-making. The Final Report[5] incorporates much of the empirical evidence from this study and explains the rationale for a proposed framework for supported decision-making which is represented in the figure below.



Diversity, Dignity, Equity and Best Practice
A Framework for Supported Decision-Making

Universal Principles

Principle 1. The equal right to make decisions
Principle 2. Support
Principle 3. Will, preferences and rights
Principle 4. Safeguards
Principle 5. Principled approach to supported decision-making
Principle 6. Best interpretation of will and preferences
Principle 7. Dignity and risk
Principle 8. Distributional equity
Principle 9. Co-leadership of people with cognitive disabilities

Elements

1. Recognising diversity in supported decision-making
2. Interrelationships with other systems
3. Use of best practice and ethical supported decision-making
4. Capacity building at individual, system and institutional levels
5. Safeguarding, quality assurance and oversight
6. Enabling forward planning
7. Adequate funding
8. Strategies to build social connections

Endnotes

[1] K Charmaz, Constructing grounded theory. A practical guide through qualitative analysis, Sage, 2006.

[2] Matthew Miles & A M Huberman, Qualitative data analysis: An expanded sourcebook (2nd ed), Sage, 1994.

[3] Shih-Ning Then, Julia Duffy, Christine Bigby, Terry Carney, Ilan Wiesel, Craig Sinclair & Jacinta Douglas, ‘Supported Decision-making: The current state of knowledge’, report prepared for the Royal Commission into Abuse, Violence, Neglect and Exploitation of People with Disability, February 2022, Appendix A Diversity, Dignity, Equity and Best Practice: A Framework for Supported Decision-Making, A Research Report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, July 2022.

[4] Ilan Wiesel, Christine Bigby, Craig Sinclair, Julia Duffy, Terry Carney, Shih-Ning Then & Jacinta Douglas, ‘Recent initiatives and programs: report of online survey results’, Appendix B Diversity, Dignity, Equity and Best Practice: A Framework for Supported Decision-Making, A Research Report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, July 2022.

[5] Christine Bigby, Terry Carney, Shih-Ning Then, Ilan Wiesel, Craig Sinclair, Jacinta Douglas & Julia Duffy, Diversity, Dignity, Equity and Best Practice: A Framework for Supported Decision-Making, A Research Report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, July 2022.

Royal Commission
into Violence, Abuse, Neglect and
Exploitation of People with Disability