



Supported Decision-Making

Background Paper – NDIS Review Engagement Project

August 2023

This paper was prepared by Shih-Ning Then and Julia Duffy to support Inclusion Australia's engagement with people living with intellectual disability, their families and allies, and other stakeholders as part of consultations to inform the NDIS Review.

Introduction

The NDIS is designed to have people with lived experience of disability at its centre. This means that people have choice and control over their funding and supports and ultimately over their own lives. And yet this can be challenging for people with intellectual disabilities. Many people with intellectual disabilities are said not to have 'legal capacity' to make decisions. This means that decisions are made for them by 'substitutes', often called 'substitute decision-makers'. This can be done formally by guardians, administrators or NDIS plan nominees or informally by family members or care/support workers.

Human rights – the right to decide

When decisions are made by substitute decision-makers, it means that people with disability may not have their own wishes – sometimes called their 'will and preferences' – listened to and respected. Often, substitute decision-makers will decide what a person with disability wants, by deciding what is in their 'best interests'. This means the substitute decision-maker may make the decision they consider to be best, rather than prioritising the wishes of the person. In many cases this means that people with disability are denied their human rights.

The 2008 *Convention on the Rights of Persons with Disabilities*¹ ('the UN CRPD') states that it is a human right for people with disability to make decisions about their own lives. Article 12 states that all people with disabilities must have their 'legal capacity' recognised. This means that they must have their decisions recognised and acted upon. The UN CRPD also provides that governments must make sure that people with disability have access to 'support' to make their own decisions. Support may require access to communication tools and independent information, but more importantly, support must be available from people – who we call 'supporters' – to help people participate in decision-making. Supporters can assist people with disability in making their own decisions and be decision-makers.

Even before the UN CRPD, practices of what is now called 'supported decision-making' existed informally and formal recognition had started overseas. Since the passing of the UN CRPD, Australia and other countries have been trialing supported decision-making practice. However, these small-scale trials have yet to be rolled out widely.

There has also been a push for guardianship and other substitute decision-making laws to recognise supporters. In Australia, only Victoria has legislation allowing for this. Other states and territories have changed their guardianship laws to recognise human rights principles. Whether or not these laws change further, supported decision-making policy and practice can still be developed.

Supported decision-making and the NDIS

The NDIS is set up under Commonwealth laws. The main law is the *National Disability Insurance Scheme Act 2013* (Cth)². In 2014 the Australian Law Reform Commission released a report – *Equality*,

¹ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 15 (entered into force 3 May 2008) ('UN CRPD'). <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

² http://www8.austlii.edu.au/cgi-bin/viewdb/au/legis/cth/consol_act/ndisa2013341/

Capacity and Disability in Commonwealth Laws ('ALRC Report').³ The ALRC Report proposed that the following four national decision-making principles be included in Commonwealth laws:

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. Laws must contain safeguards to 'prevent abuse and undue influence' in decision-making.

The ALRC Report recommended that in all cases, supported decision-making should be available and tried. It said that as a last resort a substitute (which it called a 'representative') should be able to make a decision. The disability community in Australia and overseas has generally welcomed the ALRC Report and its four decision-making principles. However, the ALRC Report focused on changes to laws, and not so much on practice or on-the-ground implementation.

The NDIS has an Independent Advisory Council and an Intellectual Disability Reference Group. This Group has asked the NDIS to introduce supported decision-making. From 2018 to 30 June 2023 the Department of Social Services gave funds to advocacy services to pilot supported decision-making. It was targeted at people with disabilities who have few or no family or friends in their lives and who need help accessing the NDIS. However there is no published information to say if this pilot worked well or not. It is therefore hard to know whether or how it could have been improved.

In 2022 the NDIS began asking the public how it should engage with supported decision-making. It released a consultation and 'companion' paper both called *Supporting you to make your own decisions*.⁴ In April 2023 the NDIS released its *NDIS Supported Decision Making Policy* ('NDIS Policy') and its *NDIS Supported Decision Making Implementation Plan*⁵ ('NDIS Implementation Plan'). The NDIS Policy adopts the four decision-making principles recommended by the ALRC Report (see above). Importantly, the NDIS Policy states that a 'Monitoring and Evaluation Strategy will be developed'. This will track the effectiveness of the implementation of the NDIS Policy over the first year. At the time of writing, this Monitoring and Evaluation Strategy had not been published and there was no other information publicly available on implementation progress.

Evidence and research

The Disability Royal Commission has been investigating supported decision-making, and how it can be best implemented. It has released a round table report⁶ and also a Research Report – *Diversity*,

³ Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws* (2014).

<https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/>

⁴ NDIS, *National Disability Insurance Scheme Consultation Paper: Supporting you to make your own decisions*. (2021). [Support for Decision Making consultation | NDIS](#)

⁵ NDIS, 'Supported decision making policy' (2023). <https://www.ndis.gov.au/about-us/policies/supported-decision-making-policy>

⁶ Abuse Royal Commission into Violence, NEglect and Exploitation of People with Disability, *Supported decision-making and guardianship - proposals for reform round table* (3 June 2022). [Roundtables | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#)

*dignity, equity and best practice: a framework for supported decision-making*⁷ ('DRC Report'). The DRC Report contains a narrative review of published literature on supported decision-making over the past ten years.⁸ It also sets out views and experiences of people with disabilities as well as family members, disability workers and advocates on decision-making. These views are as expressed in targeted focus groups.⁹ The findings from the focus groups were organised into seven categories (summarised in the table below) and form part of the evidence base for the rest of this paper.

Category	Finding
Supported decision-making – a contested concept	Supported decision-making was viewed in three main ways: 1) as the binary opposite of substitute decision-making, 2) as part of a continuum of decision-making support; or 3) as a principled approach so that the principles of supported decision-making were embedded in any form of decision support, '...so that supported decision-making is practised even when there is a guardian (advocate-carer).' ¹⁰
Furthering the exercise of rights – 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', much likely (sic) to be living the life that I want to live and be free of those abuses (self-advocate)'. ¹¹
Diverse traditions of decision support	There were differences between sectors in thinking about supported decision-making. The 'sectors' referred to were health (or medical), mental health, aged care, and disability. ¹²
Elements of a supported decision-making framework	Some suggested elements for including in a supported decision-making framework to encompass all people in need of supported decision-making included: 'Principles need to be universal – not applicable to anyone disability (advocate-disability), and 'Trying to come up with one size fits all won't work' (self-advocate). ¹³
Supported decision-making and advocacy	Supported decision-making and advocacy were viewed as different concepts that overlap: 'Supported decision-making is when I ask someone to help me make a decision – Advocacy is someone representing me (self-advocate).' ¹⁴

⁷ [Research Report - Diversity, dignity, equity and best practice a framework for supported decision-making \(royalcommission.gov.au\) Diversity, dignity, equity and best practice: a framework for supported decision-making | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](https://www.royalcommission.gov.au/diversity-dignity-equity-and-best-practice-a-framework-for-supported-decision-making)

⁸ DRC Report Appendix A.

⁹ See DRC Report Appendix C.

¹⁰ DRC Report p. 384.

¹¹ DRC Report p. 384.

¹² DRC Report pp. 388-89.

¹³ DRC Report p. 394.

¹⁴ DRC Report p.412.

Implementation obstacles	Obstacles included: variable commitment by service providers, inadequate funding, challenges around monitoring and building social networks. ¹⁵
Facilitators of supported decision-making	Facilitators included: the shift towards individualised service provision (NDIS and aged care) and the potential for existing mechanisms to be used to pay for decision support from their funding package. ¹⁶

What is the problem?

The disability community and the NDIS have expressed commitment to supported decision-making. Yet more than ten years after the adoption of the UN CRPD, the implementation journey has only just started.

Key challenges identified through research are:

- Agreeing on a common approach to understanding what supported decision-making is,
- Resolving the tension between: on the one hand, the need for a universal understanding of supported decision-making, and on the other hand, tailoring practice for diverse communities and service systems,
- Understanding how supported decision-making can be practiced effectively,
- How to best recognise supported decision-making in legal and policy frameworks,
- Educating professionals and the wider community on supported decision-making,
- Agreeing on how supported decision-making applies to people with severe and profound cognitive disability,
- Resolving how supported decision-making can work for isolated participants,
- Recognising and resolving challenges around supporting 'risky' decisions,¹⁷
- Deciding on and developing legal and non-legal safeguards, including around conflicts of interests for supporters – whether family members or workers,
- Agreeing on how supported decision-making should be resourced and funded.

What is the solution?

The NDIS Implementation Plan already identifies key outputs to address many of the above challenges. These include, for example:

- Developing resources and educating the public and sectors that engage with people with cognitive disability about supported decision-making in the NDIS,
- Improving supported decision-making practices for transition to adulthood,

¹⁵ DRC Report pp. 413-18.

¹⁶ DRC Report p. 418.

¹⁷ See guidance in NDIS, *Participant Safeguarding Policy* <https://www.ndis.gov.au/participantsafeguarding> (April 2023).

- Working with the community and government sectors to promote the use of supported decision-making, and
- Connecting participants with the decision support they need and reviewing and improving the approach to appointing nominees.

The NDIS plan sets out *what* is to be done, but the specifics of ‘how’, are still a challenge.

The DRC Report makes a range of recommendations to address these challenges. Many of these are aimed at governments, community and organisations more broadly. However, the NDIS has a key role in leading community understanding and adoption of supported decision-making.

Building upon and extending the principles from the ALRC report, the DRC Report proposes a ‘*principled*’ approach to supported decision-making. There has been ongoing confusion as to whether there is a strict binary divide between supported and substitute decision-making or whether they operate on a continuum. The principled approach affirms the ethical demand for key decision-making principles to apply in all cases. It applies the four decision-making principles in the ALRC Report (see above) but adds five more.

The nine principles are universal, but they are underpinned by seven elements¹⁸ that allow for diversity. The nine principles are summarised as:

1. **Equal right to make decisions.** All adults and youth have an equal right to make decisions that affect their lives and to have those decisions respected.
2. **Support.** All people who require support in decision-making must be provided with access to the supports to make, communicate and participate in decisions affecting their lives.
3. **Will, preferences and rights.** The will, preferences and rights of people requiring decision-making support must direct decisions that affect their lives.
4. **Safeguards.** Laws, legal and policy frameworks must contain appropriate and effective safeguards for decision-makers, including to prevent abuse and undue influence.
5. **Principled approach to supported decision-making.** A principled approach to the concept and practice of supported decision-making should be adopted. This keeps an individual’s stated or perceived ‘will and preferences’ at the centre of decision-making. It recognises the realities of the practice of providing supported decision-making, particularly for those with severe cognitive disabilities.
6. **Best interpretation of will and preferences.** In very limited circumstances a supporter may not be able to work out a person’s will and preferences. In this case a decision should be made based on the supporter’s best interpretation of the person’s will and preferences.
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 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

¹⁸ Note that the DRC Report sets out 8 elements, but not included here is ‘Enabling forward planning’. Forward planning is geared largely towards people envisaging aged dementia.

understand that risk even with support, a substitute decision can be made as a last resort. The person's personal and social wellbeing, as well as their will and preferences, must guide decision-making.

8. **Distributional equity.** All supported decision-making reform and initiatives should commit to equity of access. People experiencing disadvantage in accessing supported decision-making should be given priority.
9. **Co-leadership by people with intellectual disabilities.** People with intellectual disabilities and supporters of people with severe cognitive disabilities must lead consultation and design.

Implementation of supported decision-making principles and practice needs to happen at multiple levels. It needs to be implemented and embedded across service systems and sectors; in government, and non-government organisations, and at local and national levels. Ongoing evaluation, review and improvement needs to be embedded. Recognising these challenges, the DRC Report identified key elements to assist in implementing supported decision-making in policy, practice, and law.

The seven key elements of implementation are:

1. Recognising diversity in supported decision-making.

- Reform of law, policy and initiatives must account for the diversity of people with cognitive disability, as well as diversity of cultures, contexts and supporters.

2. Interrelationship of supported decision-making with other systems.

- Context-specific supported decision-making action plans should be produced for different service systems and institutional settings.
- NDIS nominee provisions should reflect the principled approach to supported decision-making.
- Data and trends on exercising nominee and guardianship powers under the NDIS should be collated and monitored.

3. 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.

4. Capacity building at individual, system and institutional levels.

- Capacity building of people with cognitive disabilities should foster development in decision-making skills and optimal use of available supports. Capacity building should be across a person's life course.
- Capacity building must address the diversity of people with cognitive disabilities. This includes cultural diversity and the situation of First Nations peoples.

- NDIS workforce competence frameworks should embed knowledge of and best practice in supported decision-making. The NDIS should require registered service providers to also embed these competencies.
- A proactive approach is needed to reach those we will call ‘informal’ supporters, such as family and friends. 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.
- All supporters, organisations and institutions involved with people with cognitive disabilities must have access to education on risk enablement and the positive aspects of risk-taking.
- To increase awareness, understanding and respect for disability rights and supported decision-making, there should be public awareness campaigns and relevant content embedded in the education system.

5. Safeguarding, quality assurance and oversight.

- Different approaches to safeguarding and monitoring are required for different types of supporters – paid and unpaid, formally recognised or not.
- 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 informal supporters.
- For formal supporters (paid or legally recognised) a range of measures are needed, including codes of conduct and competency standards.

6. Adequate funding.

- Adequate funding is needed for supported decision-making to be implemented in the NDIS and by registered service providers.
- The NDIS should fund supported decision-making in packages for participants who have no access to informal sources of support.

7. Strategies to build social connections.

Strategies to build social connections of people with disabilities who are socially isolated, should be prioritised. Further research and pilots are needed in this area.

The principles and strategies described above

are also set out in diagrammatic form (above) in a way that re-states the text.

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

Universal Principles	<p>Principle 1. The equal right to make decisions</p> <p>Principle 2. Support</p> <p>Principle 3. Will, preferences and rights</p> <p>Principle 4. Safeguards</p> <p>Principle 5. Principled approach to supported decision-making</p> <p>Principle 6. Best interpretation of will and preferences</p> <p>Principle 7. Dignity and risk</p> <p>Principle 8. Distributional equity</p> <p>Principle 9. Co-leadership of people with cognitive disabilities</p>
Elements	<p>1. Recognising diversity in supported decision-making</p> <p>2. Interrelationships with other systems</p> <p>3. Use of best practice and ethical supported decision-making</p> <p>4. Capacity building at individual, system and institutional levels</p> <p>5. Safeguarding, quality assurance and oversight</p> <p>6. Enabling forward planning</p> <p>7. Adequate funding</p> <p>8. Strategies to build social connections</p>

What does the evidence say?

The above summary of 'problems' and proposed 'solutions' is based on or drawn from available evidence as synthesized in the DRC Report. Importantly, the DRC Report draws on the voices of people with lived experience.

This section dives further into evidence and associated literature. There is only room for select key issues to be explored. The chosen issues are: 1. Evidence based supported decision-making practice; 2. Who can be a supporter? And finding supporters for isolated people 3. Recognition of supported decision-making in current Australian legal frameworks; 4. Supported decision-making with people with severe and profound intellectual disability; 5. Accounting for diversity; 6. Safeguards; and 7. Co-leadership and design.

1. Evidence based supported decision-making practice

The process of encouraging or allowing a person to make their own decision may seem intuitive or 'natural'. However, research shows that this is not always the case. Cultural norms and protective attitudes of family members and workers can mean that they discourage independent decision-making. Supporting decision-making can mean a significant change in approach, and new skills are needed for supporters.

Supported decision-making pilots and trials to date have been small scale with time-limited funding. They have varied in terms of rigour of practice and evaluation. The *La Trobe Framework for Supported Decision-Making* ('the La Trobe Framework')¹⁹ has however been based on funded research and results have been subject to peer review.

It comprises seven steps that are underpinned by three principles. The seven steps are, in summary:



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, and
7. Implementing the decision and seeking advocates if necessary.

¹⁹ 'The La Trobe Support for Decision Making Practice Framework Learning Resource', <https://www.supportforddecisionmakingresource.com.au/>.

In addition, three principles of practice for supporters are:

- commitment - 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.

These seven steps and three principles in the La Trobe Framework are set out in the above diagram, restating the summary in the text.

Supporters also need to be able to develop and use a range of strategies that suit the decision-maker. The research found strategies 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. To assist with decision-making, supporters often sought to: create decision-making opportunities; provide education about the practicalities and consequences of different choices; and narrow down options. Supporters paid particular attention to the communication needs of the supported person, ensuring that they listened and engaged with them. Augmentative and alternative forms of communication may be needed such as signing, assistive technologies, object references or facial expressions.

Findings confirmed the complexity of the supporter/decision-maker relationship – especially where the decision involved risk of harm to the decision-maker – and the emotional investment that most supporters put into providing support. However, having a structured approach to supporting decision-making backed up by training was found to be helpful. It encouraged parents to adopt a more reflective approach and to rethink old practices and assumptions on decision-making with the supported person. This self-awareness in turn enabled them to adopt a more rights-based approach, prioritising the person's wishes more. The self-reflection and review underpinning this framework was viewed as essential by supporters, acting as a safeguard against falling into paternalistic substitute decision-making.²⁰

2. Who can be a supporter? And finding supporters for isolated people

People acting as supporters may be family, friends, peers, independent advocates, support workers or health professionals. Supporters may have long term pre-existing relationships of trust with the person they support. However, sometimes paid professionals or support workers may fulfil a supporter role for some types of decisions.

Even when someone is already formally appointed as a guardian, administrator or nominee, they can also act as a decision supporter. This was demonstrated in trials with government workers as

²⁰ Christine Bigby et al, "'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* 1, 10.1080/09638288.2021.1964623; Christine Bigby et al, '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

supporters, undertaken in Queensland's Office of the Public Trustee and in the Transport Accident Commission (Vic). Both used the La Trobe Framework, adapted for the Public Trustee to align with the 'structured decision-making' framework in Queensland's guardianship law. Evaluations concluded that the training was successful and that workers found the structured approach useful. The fact that there was leadership across the agency prioritising the initiatives was a key facilitating factor.²¹

Finding supporters for socially isolated participants can be challenging. Much of the literature on supported decision-making assumes that support networks in the form of family and friends are already in existence. Yet the reality for many people with disability is often that they are relatively isolated, and it is this isolation that already places them at higher risk of exploitation and abuse. Research has found that those without informal support networks may lack the self-advocacy skills needed to argue for an adequate funding package, compared with those who have informal support.²² There is a significant gap in evidence about costs and strategies for building and maintaining social connections for people without existing family or informal supporters.²³ However, adequate funding is needed potentially from either or both of NDIS individual packages or the Information Linkages and Capacity (ILC) Building program, to resource capacity for building social networks. Strategies could include building self-advocacy skills and peer support.

In one trial in Victoria, volunteer supporters were recruited from the community. Decision-makers and supporters were matched together by considering personal preferences (age, gender, location etc), personalities, and the intensity of support required. The process of recruitment proved to be challenging and training and supervision time-consuming. The evaluation showed however some significant successes for the participants. One suggestion was that in the future targeted recruitment may be required to ensure appropriate matching in some cases.²⁴

3. Recognition of supported decision-making in current Australian legal frameworks

With de-institutionalisation of people with disability, States and Territories introduced formally recognised substitute decision-making, through guardianship and related laws. Substitute decision-makers may be appointed – like guardians and administrators – or recognised through health care decision-making legislation. However, the concept and practice of supported decision-making has received increasing amounts of attention – both in terms of policy development and legal reform.²⁵

²¹ DRC Report page 255; Bigby, Christine, Jacinta Douglas and Elizabeth Smith, *Considering Human Rights in Decision Making: Evaluation of the introduction of structured decision-making framework in the Public Trustee Queensland* (November 2021) <https://www.pt.qld.gov.au/media/2215/considering-human-rights-in-decision-making-evaluation-of-the-introduction-of-structured-decision-making-framework-in-the-public-trustee-queensland.pdf>

²² DRC Report page 242

²³ DRC Report page 19

²⁴ DRC Report page 124; Office of the Public Advocate (Vic)/VALiD, 'Volunteer Programs of Support for Decision-making: Lessons and recommendations from the OVAL project', Office of Public Advocate (Vic), 2017: 23 >.

²⁵ See e.g., pilot projects described at Bigby, Christine 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) 52(3) *Australian Journal of Social Issues* 222, App A, [9.4] DOI: 10.1002/ajs4.19. See also, National Disability Insurance Agency, *NDIS Supported Decision Making Policy* (April 2023) < <https://www.ndis.gov.au/about-us/policies/supported-decision-making-policy>>.

Law reform agencies in Australia have been particularly supportive of the idea of introducing aspects of supported decision-making into Australian law.²⁶ However, this has not always translated into legal reform.

The law as it currently stands in the Australian States and Territories recognises the principles underpinning supported decision-making in the following ways:

- Through legal principles that require that attempts be made to support a person to make their own decision before any substitute decision is made,
- Through legal principles that seek to prioritise a person's 'will and preferences' when a substitute decision does have to be made,²⁷
- In Victoria, legally recognised supporters can be appointed by a person or by the Tribunal.

Legal reform continues to occur in Australia, mainly through incremental improvement of existing substitute decision-making frameworks. These are being reformed to prioritise supported decision-making principles over paternalistic 'best interests' principles.

4. Supported decision-making with people with severe and profound cognitive disability

Most supported decision-making trials in Australia and overseas have involved people with mild to moderate intellectual disability. There is an ongoing question around how people with severe and profound cognitive disability can be included in supported decision-making. The United Nations Committee that monitors implementation of the UN CRPD has proposed that a supporter must make a 'best interpretation' of the person's will and preferences.²⁸ The Australian Law Reform Commission recommends more broadly that the will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.²⁹

In a first-hand account, a mother 'Tracy' described supported decision-making with her son 'Nick'. Nick has significant physical and intellectual disabilities. Tracy describes how decisions with 'potentially serious implications' are made. These include decisions on: diet, surgery, accommodation, unsafe activities and potentially criminal behaviour. Tracy asserts that many of these decisions must ultimately be made by the supporter. She notes that communication is at the core, so supporting Nick requires an 'intimate understanding' of his personality. She stresses it is

²⁶ Shih-Ning Then et al, 'Supporting Decision-making of Adults with Cognitive Disabilities: The role of Law Reform Agencies – Recommendations, Rationales and Influence' (2018) 61 *International Journal of Law and Psychiatry* 64. *Equality, Capacity and Disability in Commonwealth Laws Report* ch 3 [Equality, Capacity and Disability in Commonwealth Laws \(ALRC Report 124\) | ALRC](#); NSW Law Reform Commission, *Review of the Guardianship Act 1987* (2018) [Review of the Guardianship Act 1987 \(nsw.gov.au\)](#); Victorian Law Reform Commission, *Guardianship: Final Report 24* (2012) ch 8, 9 [Guardianship - Victorian Law Reform Commission](#).

²⁷ Bigby, Christine 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) 52(3) *Australian Journal of Social Issues* 222 App A, [8.3.1] DOI: 10.1002/ajs4.19.

²⁸ UN Committee on the Rights of Persons with Disabilities, *General Comment No. 1 (2014) Article 12: Equal Recognition Before the Law CRPD/C/GC/1 (2014)* (2014) [General Comment No. 1 - Article 12 : Equal recognition before the law \(Adopted 11 April 2014\) - Plain English version | OHCHR](#)

²⁹ Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report* (2014) p. 11...

very important that he make his own decisions, but that it is very complex. Strategies involve an ongoing dialogue, checking with him that he has 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. Tracy advocates for balancing a 'duty of care' with the 'dignity of choice'.³⁰

The experience of Tracy and Nick accords with wider research. One study of parental decision supporters did include four people with high support needs. Findings showed the importance of knowing the person well, but also careful observation to identify behaviour that signals preferences. Further understanding of preferences could be gained from sharing and seeking information from other supporters or service users.³¹ Research on practice shows how support and substitution are viewed as existing along a continuum.³²

5. Accounting for diversity

The specific situations of a range of people from different communities need to be considered in designing supported decision-making systems. These people include children and youth, older people, people from culturally diverse groups, First Nations communities, and the LGBTIQ+ community. Moreover, many people identify with several of these intersecting attributes, and this intersectionality can increase a person's vulnerability and risk of discrimination in decision-making and service provision. Supported decision-making must be responsive to individual needs and preferences and respect diversity and identity.³³

There is a lack of research on supported decision-making in culturally diverse groups. This is a significant gap. There is a higher rate of disability in First Nations communities, including mild to borderline intellectual disability, and acquired brain injury. People in First Nations communities are also disproportionately impacted by guardianship orders.³⁴ The Office of the Public Advocate (Vic) has published guidance for its staff on interacting with First Nations clients.³⁵ Similar guidance on decision-making support and cultural capability is required in other contexts, including the NDIS.³⁶

One available tool is: *Skilled to Thrive: Support to make decisions that promote personal safety and prevent harm*. This was developed by the University of New South Wales Social Policy Research Centre for the NSW Council of Social Service. It was based on (unpublished) research conducted with the Sydney Regional Aboriginal Corporation and the Multicultural Disability Advocacy Association of NSW. The research involved interviewing people with disability and workers to develop a practice guide for workers supporting people with disability to make decisions about personal safety and

³⁰ DRC Report, page 183.

³¹ Bigby et al, 'Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences' (n [Full article: Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences \(tandfonline.com\)](#))

³² Shih-Ning Then et al, 'Moving from Support for Decision-making to Substitute decision-making: Legal Frameworks and Perspectives of Supporters of Adults with Intellectual Disabilities' (2021) 37(3) *Law in Context*.

³³ See [LGBTIQ+ Strategy | NDIS](#), and [Cultural and Linguistic Diversity Strategy | NDIS](#)

³⁴ [Submission to the Disability Royal Commission on Guardianship and Substituted Decision Making – Inclusion Australia](#)

³⁵ Office of the Public Advocate (Vic), *Walk with Me, Talk with Me: A Practice Guide for OPA staff* (1 July 2019). <https://www.publicadvocate.vic.gov.au/opa-s-work/our-organisation/diversity-and-inclusion/171-walk-with-me-talk-with-me>

³⁶ See the [First Nations Strategy | NDIS](#).

wellbeing and preventing harm. This has resulted in a *Literature and Practice Review*³⁷ and the *Tree of Life* practice guide.³⁸

The DRC Report found that the impact of cultural diversity on decision-making and people with cognitive disability is under-investigated. Further research is needed. Preliminary and anecdotal findings do however suggest that some cultures promote paternalism and protection in the family sphere more than others. There may also be differences in decision making between cultures that prioritise individuality, as opposed to those that prioritised family and community. Other research (specific to financial decision-making) found that cultural background could lead financial advisors to misinterpret behaviours and communications.

6. Safeguards

There is no agreement on what safeguards are needed and appropriate for trustworthy and effective supported decision-making.

There is wide consensus that strict government regulation of the relationship between a decision-maker and informal supporter (family or friends) is inappropriate. On the other hand, there is recognition that people with disabilities are disproportionately subject to abuse by those around them.

There is some agreement that governments or non-government agencies should have a role in regulating 'formal' supporters. These are supporters who get paid for their services, or who volunteer their services to people outside of their family and friendship circle, or who are legally recognised as a supporter (or substitute decision-maker).

Preventative safeguards can include: registration of supporters, exclusion of certain people from a supporter role and education for supporters. Victoria already has in place a system for registration of supporters (called 'supportive guardians'),³⁹ which is optional. There is, however, scant data on their use and no evaluations of their effectiveness.

The research does reveal widespread views that effective safeguarding must include:

- having a trusted person who knows the decision-maker well,
- ideally having more than one supporter,
- supporting people with disability to make decisions from an early age,
- educating the community more widely,
- applying evidence-based practise frameworks, and
- enabling social inclusion.

³⁷ Sandra Gendera et al, *Skilled to Thrive: Support to make decisions that promote personal safety and prevent harm* (July 2017). [Skilled to Thrive Project Plan: Support to make decisions that promote personal safety and prevent harm – My Rights: Supported Decision Making](#)

³⁸ NSW Council of Social Service, *The Tree of Life Practice Guide* (2018). [Supporting decision making and problem solving using the Tree of Life - NCOSS - NSW Council of Social Service](#)

³⁹ See :[Your supported personal and financial decisions - Office of the Public Advocate](#)

The NDIS SDM policy already includes some safeguards. It says that a participant may choose a support person to make NDIS related decisions, and that supporters will be noted in NDIS records. Also noted will be the particular types of decisions for which the person will be giving support.

Safeguarding suggestions put forward as part of the research for the DRC Report included the possibility of formal supporters documenting their decision support practices.

7. Co-leadership and design

Moving supported decision-making forward in Australia requires people with lived experience to be part of, and leaders in, this conversation. The importance of this issue to people with cognitive disabilities was highlighted in the DRC report that heard the voices of people with lived experience. For example, they say that:

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

Supported decision-making is about looking forward ...about how do you navigate your next step...

[supported decision-making] helps people to be able to tell the world what they want,...

Many organisations already have people with intellectual disability involved in co-design of supported decision-making initiatives. The NDIA formed a 'Co-design Steering Committee' for 'Support for Decision Making which dissolved on release of the NDIS Policy in April 2023.⁴⁰ However, there is little evidence in the literature as to the best models of co-design/leadership for developing law, policy and practice. This is an area that requires further research and investment. Finally, further research is also needed to ensure people with more severe or profound cognitive disabilities are not excluded from co-leadership and co-design efforts.

⁴⁰ [Working towards co-design | NDIS](#)

Bibliography

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

Bigby, Christine 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) 52(3) *Australian Journal of Social Issues* 222 DOI: 10.1002/ajs4.19

Bigby, Christine et al, "'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* 1 10.1080/09638288.2021.1964623

Bigby, Christine et al, '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

Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 2515 UNTS 15 (entered into force 3 May 2008) <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>

Genera, Sandra et al, *Skilled to Thrive: Support to make decisions that promote personal safety and prevent harm* (July 2017) [https://supporteddecisionmaking.com.au/wp-content/uploads/sites/4/2022/05/2021-06-Skilled to Thrive research project plan-1.pdf](https://supporteddecisionmaking.com.au/wp-content/uploads/sites/4/2022/05/2021-06-Skilled_to_Thrive_research_project_plan-1.pdf)

'The La Trobe Support for Decision Making Practice Framework Learning Resource', <https://www.supportfordecisionmakingresource.com.au/>

Inclusion Australia, [Submission to the Disability Royal Commission on Guardianship and Substituted Decision Making – Inclusion Australia](#)

La Trobe Support for Decision Making Practice Framework Learning Resource, <https://www.supportfordecisionmakingresource.com.au/>.

NDIS, *Cultural and Linguistic Diversity Strategy*, [Cultural and Linguistic Diversity Strategy | NDIS](#)

NDIS, *First Nations Strategy*, [First Nations Strategy | NDIS](#)

NDIS, *LGBTIQ+ Strategy*, [LGBTIQ+ Strategy | NDIS](#),

NDIS, *National Disability Insurance Scheme Consultation Paper: Supporting you to make your own decisions*. (2021)). [Support for Decision Making consultation | NDIS](#)

NDIS, 'Supported decision making policy' (2023) <https://www.ndis.gov.au/about-us/policies/supported-decision-making-policy>

NDIS, *Participant Safeguarding Policy* <https://www.ndis.gov.au/participantsafeguarding> (April 2023)

NSW Council of Social Service, *The Tree of Life Practice Guide* (2018) <https://www.ncoss.org.au/wp-content/uploads/2018/06/Tree-of-Life-Practice-Guide-final.pdf>

NSW Law Reform Commission, *Review of the Guardianship Act 1987* (2018) [Review of the Guardianship Act 1987 \(nsw.gov.au\)](#)

Office of the Public Advocate (Vic), *Walk with Me, Talk with Me: A Practice Guide for OPA staff* (1 July 2019) [Walk with Me, Talk with Me - Office of the Public Advocate](#)

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Supported decision-making and guardianship - proposals for reform round table* (3 June 2022) [Roundtables | Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability](#)

Then, Shih-Ning et al, 'Supporting Decision-making of Adults with Cognitive Disabilities: The role of Law Reform Agencies – Recommendations, Rationales and Influence' (2018) 61 *International Journal of Law and Psychiatry* 64

Then, Shih-Ning et al, 'Moving from Support for Decision-making to Substitute decision-making: Legal Frameworks and Perspectives of Supporters of Adults with Intellectual Disabilities' (2021) 37(3) *Law in Context*

UN Committee on the Rights of Persons with Disabilities, *General Comment No. 1 (2014) Article 12: Equal Recognition Before the Law CRPD/C/GC/1 (2014)* (2014) [General Comment No. 1 - Article 12 : Equal recognition before the law \(Adopted 11 April 2014\) - Plain English version | OHCHR](#)

Victorian Law Reform Commission, *Guardianship: Final Report 24* (2012) [Guardianship - Victorian Law Reform Commission](#)