Supported decisionmaking for people living with dementia in NSW

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Key points

- Dementia affects hundreds of thousands of Australians and is a leading cause of disability and death.
- Dementia leads to a progressive decline in a person's ability to make decisions about their
 personal lives, their finances and their healthcare. People living with dementia will need help
 making those decisions and, as dementia progresses, they may no longer be able to be
 involved in decision-making at all when they have permanently lost mental capacity.
- Supported decision-making is an approach to decision-making that requires support to be
 given to a person living with a disability (like dementia) to enable them to make decisions. It
 requires that the will and preferences of a person living with dementia remain at the centre
 of decision-making.
- Supported decision-making is mandated by Australia's ratification of the United Nations
 Convention on the Rights of Persons with Disabilities. The Australian Government and some
 state and territory jurisdictions have made changes to their laws to enact supported
 decision-making.
- NSW has implemented supported decision-making into its policy frameworks but has not
 updated its laws on decision-making to include supported decision-making. In the future
 this may lead to difficulties arising as NSW law conflicts with Commonwealth laws that are
 concerned with decision-making for people living with dementia.

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1. Introduction

Supported decision-making is a legal principle that requires individuals with impaired capacity to be provided with assistance so they can be empowered to make their own decisions. This assistance can come in various forms, such as the provision of language support, visual aids, or other means that are tailored to an individual to enable them to decide questions about their lifestyle, finances and healthcare. A supported decision-making approach requires that when a person is not able to make their own decisions even if supported, decision-making be driven by their will and preferences.

'Dementia' is an umbrella term that includes a number of medical syndromes that are all associated with a chronic, neurodegenerative decline that leads to loss of cognition and death.² Characteristically, dementia results in impairments in language, memory and perception. Dementia also negatively affects higher order brain functions, including attention, emotional regulation and decision-making. Dementia typically has a gradual progression, but often people with dementia will have periods of stability in their condition and then periods of rapid change. While it is possible for children to have dementia (caused by variety of genetic disorders), most people living with dementia are over the age of 65.³ To date there are no long-term effective therapies or treatments for dementia (Box 1).

The size and scale of dementia in Australia means that everyone in Australia will be affected by dementia at some stage in their lives, either as a person living with dementia or as a partner, family member, or friend of someone with dementia.

¹ C Sinclair, et al., <u>Supporting decision-making: A guide for people living with dementia, family members and carers</u>, Cognitive Decline Partnership Centre, 2018.

² Australian Institute of Health and Welfare, <u>Dementia in Australia</u>, 12 September 2025, accessed 20 September 2025.

³ Department of Health, Disability and Ageing, *About dementia*, 6 June 2025, accessed 20 September 2025.

Box 1: Size and scale of dementia in Australia

- There are over 100 different medical conditions that can cause dementia. The most common types include Alzheimer's disease, vascular dementia, Lewy body dementias (including dementia with Lewy bodies and Parkinson's disease dementia), and frontotemporal dementia.
- Dementia is not part of the 'normal' process of ageing, even though age is a key risk factor.
- There is not a single conclusive test for diagnosing dementia. Diagnosis of dementia is complex and may take time.⁴
- There is no cure for dementia. There are some treatments that may temporarily slow the progression of cognitive decline (such as cholinesterase inhibitors).
- In 2025, an estimated 433,300 people in Australia are living with dementia, and this is
 projected to increase to 812,500 people by 2054. In NSW, there is an estimated 141,800
 people living with dementia in 2025, with a projected increase to 252,800 by 2054.⁵
- Dementia was the second leading cause of burden of disease in Australia in 2023. It was the leading cause of burden for women as well as for Australians aged 65 and over. 6
- In 2022, dementia was the second leading cause of death in Australia, accounting for just under 17,800 deaths (or 9.3% of all deaths). Dementia was the leading cause of death for women and the second leading cause for men, after coronary heart disease.⁷
- The Australian Institute of Health and Welfare (AIHW) reports \$3.7 billion of direct health and aged care expenditure was attributed to dementia during 2020-21.8

The purpose of this paper is to examine how the law in NSW creates frameworks for decision-making for people living with dementia. Because of its ongoing and irreversible nature, the difficulties with cognition that can affect the ability of people living with dementia to understand and process information will inevitably increase and they will eventually lose the capacity to make decisions. This means that decisions will have to be made by others, a situation that is generically known as surrogate decision-making or substitute decision-making.

This paper describes the traditional models for surrogate decision-making that arise when a person living with dementia loses their capacity – the best interests test and substituted judgment – and how these are currently manifested in legislative and policy frameworks in NSW. The main focus of the paper is on supported decision-making, which is a third model of decision making that is

⁴ Cognitive Decline Partnership Centre Guideline Adaptation Committee, <u>Clinical Practice Guidelines and Principles of Care for People with Dementia</u>, 2016.

⁵ Dementia Australia, <u>Dementia Facts and Figures</u>, 6 February 2025, accessed 15 September 2025.

⁶ 'Burden of disease' refers to the quantified impact of living with and dying prematurely from a disease or injury and is measured by disability-adjusted life years (DALY). One DALY is equivalent to one year of healthy life lost. Australian Institute of Health and Welfare, <u>Dementia in Australia</u> 12 September 2025, accessed 20 September 2025.

⁷ Australian Institute of Health and Welfare, <u>Dementia in Australia</u>, 12 September 2025, accessed 20 September 2025.

⁸ Australian Institute of Health and Welfare, <u>Dementia in Australia</u>, 12 September 2025, accessed 20 September 2025.

becoming more common due to Australia's legal obligations under the Convention on the Rights of Persons with Disabilities (CRPD).

The CRPD was originally developed to assist people with intellectual disability or mental illness, however people living with dementia have been expressly recognised as being 'persons with disabilities' coming within the scope of the CRPD. People living with dementia differ in one major respect from these populations, as their disability is one of terminal and irreversible decline in cognition. This raises challenges for the implementation of supported decision-making and it is important to design support for people living with dementia knowing that, at some point, the person will not be able to make a decision regardless of support.

The paper also describes how supported decision-making has been implemented in other Australian jurisdictions, including specific cases of how supported decision-making laws and principles have been applied in practice in Victoria. It highlights some challenges that NSW will face in this area, particularly in the context of models of supported decision-making that are being introduced at a national level through the new *Aged Care Act 2024* (Cth). The commencement of this Act in November 2025 provides an opportunity for law reform in NSW to ensure that the approaches and standards for decision-making that apply in the care and management of people living with dementia are aligned.

⁹N Batsch et al., <u>Access to the United Nations Convention on the Rights of Persons with Disabilities by people living with dementia</u>, Alzheimer's Disease International and Dementia Alliance, August 2017, accessed 29 September 2025.

¹⁰ M Blake, <u>People Living with Dementia: What Difference Does Statutory Change Make? A Case Study from Australia, *Medical Research Archives*, 2025, 13(1), doi: 10.18103/mra.v13i1.6135.</u>

2. Decision-making models for people living with dementia

Like everyone, people living with dementia have to make a number of important lifestyle, financial and health care decisions. Inevitably, they will face difficulties when dementia begins to cause them to experience progressive cognitive impairment. As decision-making becomes more difficult, people living with dementia will have to rely on increasing assistance from others to make decisions and, eventually, they will be unable to make those decisions and/or communicate them. ¹¹ If a person with dementia lacks capacity there have traditionally been two kinds of models that are employed to make decisions about their lifestyle, finances and healthcare: the *best interests test* and *substituted judgment*. With the introduction of the CRPD a third model of decision-making was recognised – *supported decision-making*. This section examines all 3 models of decision-making, and the next analyses how these models have been employed to varying degrees in NSW. Box 2 sets out the key terminology used in this discussion.

Box 2: Terminology related to decision-making models

Capacity: Ability of a person to make legally binding decisions. The law has different tests for capacity depending on the type of activity.

Surrogate decision-making: A general term that refers to any process or model for making a decision on behalf of someone else who has lost capacity.

Best interests: Where a person makes a decision on behalf of a person who has lost capacity on the basis of what they think is in the best interests of the person.

Substituted judgement: Where a person makes a decision on behalf of a person who has lost capacity that attempts to best match what the person would have decided if they had capacity.

Supported decision-making: Where a person provides support to a person who has lost capacity so that they have the capacity to make their own decisions; or, when capacity is no longer achievable, a person makes a decision on behalf of the person that reflects their will and preferences.

2.1 Legal definitions of capacity

In the common law, the ability of a person to make legally binding decisions is referred to as 'mental capacity'. In NSW every person aged 18 years and older is assumed to have the capacity to make

¹¹ F Gaubert, H Chainay, <u>Decision-Making Competence in Patients with Alzheimer's Disease: A Review of the Literature</u>, *Neuropsychological Review*, 2021, 31: 267–287, doi: 10.1007/s11065-020-09472-2.

decisions concerning their personal life, legal affairs and healthcare. ¹² In cases where a person's capacity to make a decision is questioned, the law requires that that person's capacity be disproven before they are found to lack mental capacity.

The law has different tests for capacity depending on the type of activity (for example, signing a contract, making a will or consenting to medical treatment). All these tests are centred on the need for the person to demonstrate that they can:

- Understand relevant information as to why the decision must be made
- Weigh that information to make a decision
- Communicate the decision to others. 13

While dementia progressively leads to a loss of capacity, a diagnosis of dementia does not automatically mean that a person lacks capacity. Capacity may fluctuate over time. It is therefore important to assess the capacity of a person living with dementia for particular decisions, in particular contexts. It is also important to recognise that, eventually, a person with dementia will reach a point in their lives when their capacity will not return, regardless of the support that may be provided to them. ¹⁴ In such cases, a decision-maker will then have to make decisions for the person living with dementia and it is in this context that different decision-making models have arisen.

There are also statutory definitions of incapacity employed in Australian jurisdictions that are very similar to the common law ones. ¹⁵ For example, NSW and other jurisdictions define incapacity by reference to an inability to understand the general nature and effect of the proposed treatment, or an inability to communicate whether or not a person consents to the treatment being proposed. ¹⁶

2.2 The best interests test

When a person lacks mental capacity, others must make decisions for them in a process of surrogate decision-making. The best interests test is the traditional test employed in these situations. The test originated in legal cases in the Supreme Court's *parens patriae* jurisdiction. This jurisdiction is part of the Crown's power to care for infants, and adults with impaired capacity. ¹⁷

The best interests test requires the decision-maker to consider a broad range of objective issues (concerning knowledge of the general benefits and risks of making a particular decision) and subjective issues (about how a decision may specifically impact an incapacitated person in the current circumstances). A checklist for these kinds of considerations is set out in Box 3.

¹² Minors (Property and Contracts) Act 1970 (NSW), s 9.

¹³ C Stewart, P Biegler, A Primer on the Law of Competence to Refuse Medical Treatment, Australian Law Journal, 78(5): 325-342.

¹⁴ C Stewart, P Biegler, A Primer on the Law of Competence to Refuse Medical Treatment, Australian Law Journal, 78(5): 325-342.

¹⁵ S Lamont, C Stewart, M Chiarella, <u>Capacity and consent: Knowledge and practice of legal and healthcare standards</u>, <u>Nursing Ethics</u>, 2019, 26(1): 71-83, doi: 10.1177/0969733016687162.

¹⁶ Guardianship Act 1987 (NSW), s 33(2); Guardianship of Adults Act 2016(NT), s 5; Advance Care Directives Act 2013 (SA), s

^{7;} Guardianship and Administration Act 2019 (Vic), s 5; Medical Treatment Planning and Decisions Act 2016 (Vic), s 4.

¹⁷ I Kerridge, M Lowe and C Stewart, Ethics and law for the health professions, 4th edn, Federation Press, 2013, p 395.

The best interests test is often criticised for being uncertain. ¹⁸ Apart from a list of factors like those shown in <u>Box 3</u>, there is no definitive test of best interests at common law. ¹⁹ Nor has the best interests test been defined in NSW legislation. ²⁰ The best interests test has also been criticised for being paternalistic as it does not prioritise the incapacitated person's own values and preferences in decision-making over other factors. ²¹

Box 3: Factors to consider in the best interests test

In Re Marion (No 2)²² Nicholson CJ applied the best interests test by creating a checklist of factors to consider. In this case the judge had to decide whether to consent to a medical treatment for an incapacitated teenage girl. The factors included:

- (1) The particular condition of the patient which requires the procedure or treatment;
- (2) The nature of the procedure or treatment proposed;
- (3) The reasons for which it is proposed that the procedure or treatment be carried out;
- (4) The alternative courses of treatment that are available in relation to that condition;
- (5) The desirability of and effect of authorising the procedure or treatment proposed rather than the available alternatives;
- (6) The physical effects on the patient and the psychological and social implications for the patient of:
 - (a) authorising the proposed procedure or treatment
 - (b) not authorising the proposed procedure or treatment
- (7) The nature and degree of any risk to the patient of:
 - (a) authorising the proposed procedure or treatment
 - (b) not authorising the proposed procedure or treatment
- (8) The views (if any) expressed by the carers of the patient:
 - (a) the guardian(s) of the patient;
 - (b) the relatives of the patient;
 - (c) a person who is responsible for the daily care and control of the patient;
 - (d) the patient;

to the proposed procedure or treatment and to any alternative procedure or treatment.

¹⁸ H Taylor, <u>What are 'Best Interests'? A critical Evaluation of 'Best Interests' Decision-making in Clinical Practice</u>, <u>Medical law Review</u>, 2016. 24(2):176-205, doi:10.1093/medlaw/fww007.

¹⁹ C Stewart, Capacity, Participation and Values in Australian Guardianship Laws, in C Kong, et al. (eds), *Capacity, Participation and Values in Comparative Legal Perspective*, Bristol University Press, 2023, p 120-142.

²⁰ Northern Territory of Australia v EH [2021] NTSCFC 5.

²¹ J Coggon, <u>Best Interests, Public Interest, and the Power of the Medical Profession</u>, *Health Care Analysis*, 2008, 16: 219–232, doi: 10.1007/s10728-008-0087-7.

²² Re Marion (No 2) (1992) 17 Fam LR 336.

There are many cases where the best interests test has been used to make decisions for people with dementia. Courts have employed the best interests test to order testing of the capacity of a person living with dementia; ²³ to make decisions regarding the finances of people living with dementia (such as whether a person needs a financial manager); ²⁴ to make personal decisions for people living with dementia (such as where a person shall live and who is allowed to visit them) ²⁵ and to make healthcare decisions for people living with dementia. ²⁶

2.3 Substituted judgment

Substituted judgment is an alternative surrogate decision-making approach to the best interests test. Under substituted judgment, when a person lacks capacity, a decision-maker should attempt to make a decision that best matches what the incapacitated person would have decided if they had capacity. ²⁷ To do this the decision-maker must take into account the personal characteristics of the patient such as preferences, religious beliefs, strongly-held beliefs, and their attitudes to personal, financial and health issues. ²⁸ The limitations of such an approach are that it may be difficult in some cases to know what a person would have decided, but advocates of substituted judgement have argued that this approach accords with the liberty of the individual (more so than the best interests test). ²⁹

The substituted judgment approach originated in early mental health law (referred to as the 'lunacy jurisdiction') in relation to the management of estates of the mentally ill.³⁰ The approach is also very commonly applied in North American jurisdictions. It was later adopted, in part, in guardianship law reforms in Australia in the 1980s.³¹

2.4 Supported decision-making

Supported decision-making emerged in the context of the CRPD, which was adopted by the United Nations in 2006 and to which Australia became a signatory in 2009. Overall, Article 12 requires states to employ supported decision-making as a way of securing equal legal capacity. This, in turn, requires decision-makers to make decisions on the basis of the rights, will and preferences of the person with a disability. ³² The relevant provisions of the CRPD are set out in Box 4.

²³ Washington v Washington [2018] SASC 102.

²⁴ Scott v Scott [2012] NSWSC 1541.

²⁵ WW v AJFW [2024] NSWSC 754; Rodgers, in the matter of Anderson [2023] NFSC 7; EB v GB (No 2) [2022] NSWSC 1011.

²⁶ Northern Territory of Australia v EH [2021] NTSCFC 5.

²⁷ GJM [2024] QCAT 166.

²⁸ I Kerridge, M Lowe and C Stewart, Ethics and law for the health professions, 4th edn, Federation Press, 2013.

²⁹ See cases from the United States such as *In Matter of Conroy* 486 A 2d 1209 (1985); *Superintendent of Belchertown v Saikiewicz* 370 NE 2d 417 (1977) at 430; *Guardianship of Doe* 583 NE 2d 1263 (1992) at 1268; *Matter of Moe* 432 NE 2d 712 (1982); *Re Weberlist* 360 NYS 2d 783 (1974).

³⁰ S Garton, <u>The rise of the therapeutic state: psychiatry and the system of criminal jurisdiction in New South Wales, 1890–1940</u>, *Australian Journal of Politics & History*, 1986, 32(3): 378-388, doi: 10.1111/j.1467-8497.1986.tb00884.x; A Renton, *The law of and practice in lunacy: with the Lunacy Acts 1890-91*, Edinburgh, Green & Sons, 1896.

³¹ T Carney and D Tait, The adult guardianship experiment: tribunals and popular justice, Federation Press, 1997.

³² See ICV (Guardianship) [2025] VCAT 463.

Box 4: Provisions in the Convention on the Rights of Persons with Disabilities that relate to supported decision-making

Article 12: Persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

Article 12(3): States must provide people with disabilities with support so that this right to legal capacity can be made effective.

Article 12(4): Safeguards must ensure that measures relating to legal capacity respect the rights, will, and preferences of the person.

There are many different approaches to supported decision-making, but at its core, supported decision-making is a model that requires decision-makers to provide support to people living with dementia so that they either have the capacity to make their own decisions, or, when capacity is no longer achievable, they will have decisions that reflect their will and preferences made for them by others. ³³ This support should be tailored to the specific needs of a person living with dementia. It can include various forms of assistance such as:

- Using information provided in formats that are easier for the person living with dementia to understand and employ in their decision-making
- Providing communication assistance to the person living with dementia by allowing time and providing information in more easily digestible formats
- Enhancing the environment in which the decision will be made to support the person's capacity.³⁴

Supported decision-making also requires that the support person be free of conflicts of interest, that they be trustworthy, that they are skilled at providing support to people with impaired capacity, and that they are conscientious about ensuring that decisions reflect the will and preferences of the person.³⁵

<u>Figure 1</u> illustrates how principles of supported decision-making can guide decision-making by professionals and family members across the spectrum of mild, moderate and advanced dementia.³⁶

³³ C Sinclair, et al., <u>Supporting decision-making: A guide for people living with dementia, family members and carers</u>, Cognitive Decline Partnership Centre, 2018.

³⁴ C Sinclair, et al., <u>Supporting decision-making: A guide for people living with dementia, family members and carers,</u> Cognitive Decline Partnership Centre, 2018.

³⁵ C Sinclair, et al., <u>Supporting decision-making: A guide for people living with dementia, family members and carers</u>, Cognitive Decline Partnership Centre, 2018.

³⁶ C Sinclair et al, <u>"A Real Bucket of Worms": Views of People Living with Dementia and Family Members on Supported Decision-Making</u>, *Journal of Bioethical Inquiry*, 2019, 16(4): 587-608, doi: 10.1007/s11673-019-09945-x.

Figure 1: Strategies for supported decision-making in dementia

LEVELS OF INTERVENTION	MILD	STAGE OF DEMENTIA MODERATE	ADVANCED	
SUPPORTERS, FAMILY & PERSON WITH DEMENTIA	Maintain/develop social networks. Discuss decision-making approaches. Nominate supporters and/or representatives. Document future wishes.	Refine practice in providing support for the person with dementia. Use prevailing principles in navigating transitions in decision-making.	Provide support where this is possible and ethically acceptable. Use representative decision-making as a last resort, in ways that are proportionate to the person's needs.	
PROFESSIONALS (e.g. DOCTORS, LAWYERS, SOCIAL WORKERS)	Promote understanding of dementia. Establish where informal support networks are and work with the person with dementia to engage networks. Allow extra time to facilitate decision-making for people with dementia.	Mentor supporters in effective techniques. Oversee supported decision-making agreements and flag potential abuse. Facilitate processes of transition in decision-making where required.	Mentor supporters and representatives. Facilitating communication between the person's identified supporters, and facilitate communication of the person's documented will and preferences between service providers.	
POLICY	 Address dementia-related stigma and promote social inclusion across the community and within institutions. Fund post-diagnostic support services from practitioners. Meaningful service options for people in diverse settings (e.g. rural, culturally and linguistically diverse). Provide education about supported decision-making and the supporter and representative roles. Fund a professional supported decision-making facilitator role. 			
PREVAILING PRINCIPLES (APPLICABLE ACROSS ALL STAGES)	 A person's ascertainable will and preference should always be given regard in decision-making. There should be a presumption of decision-making abiility and any assessment process should be sensitive, time- and decision-specific, mindful of relational contexts, and geared towards understanding the person's need for support. Supportive interventions should address potential sources of undue influence in decision-making, in keeping with the principle of 'voluntariness'. Supportive interventions should be tailored for both the person with dementia and others in the decision-making process. Supportive interventions should aim to maintain or develop the person's existing informal support networks. Any intervention should be 'tailored', 'proportionate', and 'least restrictive' of the person's freedom. Where there is no ascertainable will and preference, a person's previously expressed will and preferences, historical decisions, and overarching human rights should direct decision-making. 			

Source: Adapted from C Sinclair et al, <u>"A Real Bucket of Worms"</u>: <u>Views of People Living with Dementia and Family Members on Supported Decision-Making</u>, *Journal of Bioethical Inquiry*, 2019, 16(4): 587-608.

Supported decision-making has been shown to provide demonstrable benefits to people living with dementia through the feelings of autonomy, respect and inclusion that come with making decisions about their personal life, finances and healthcare.³⁷ For example, in one study, people living dementia described involvement in decision-making as an important means of affirming their self-identity and confirmation that they were still considered to be important and valued.³⁸

³⁷ C Sinclair, et al., <u>Supporting decision-making</u>: A guide for people living with dementia, family members and carers, Cognitive Decline Partnership Centre, 2018.; Sinclair C et al, <u>How couples with dementia experience healthcare, lifestyle, and everyday decision-making</u>, <u>International Psychogeriatrics</u>, 2018, 30(11),1639-1647, doi: 10.1017/S1041610218000741; L Pritchard-Jones, <u>Ageism and Autonomy in Health Care</u>: <u>Exploration Through A Relational Lens</u>, Health Care Analysis, 2017, 25(1): 72-89, doi: 10.1007/s10728-014-0288-1.

³⁸ D Fetherstonhaugh, L Tarzia and R Nay, <u>Being central to decision making means I am still here!</u>: <u>The essence of decision making for people with dementia</u>, <u>Journal of Aging Studies</u>, 2013, 27:143-50, doi: 10.1016/j.jaging.2012.12.007.

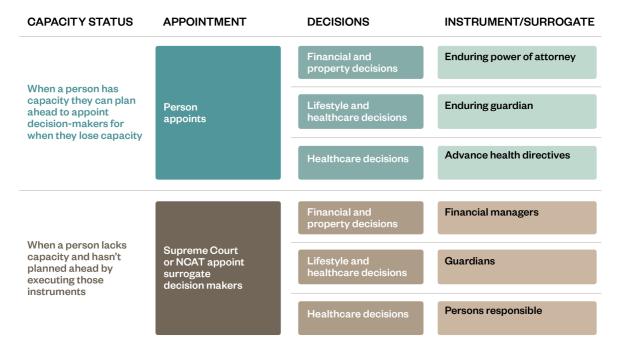
Studies in Australia have argued that a lack of formal legal recognition for supported decision-making makes it more difficult to implement this model.³⁹ This highlights the importance of clarity in the regulation of supported decision-making.

³⁹ C Bigby et al, <u>Delivering decision making support to people with cognitive disability — What has been learned from pilot programs in Australia from 2010 to 2015, Australian Journal of Social Issues, 2017, 52:222–240,doi: 10.1002/ajs4.19.</u>

3. Current decision-making frameworks for people living with dementia in NSW

This section examines current decision-making frameworks in NSW for people living with dementia. It begins by considering how people living with dementia can plan ahead by appointing enduring powers of attorney and enduring guardians, and by making advance care directives. It then examines decision-making processes for people who lack capacity when this type of advance planning has not occurred, via the appointment of financial managers, guardians and the system of persons responsible for healthcare decisions. Figure 2 sets out the legal decision-making frameworks and instruments discussed in this section.

Figure 2: Current legal decision-making frameworks and instruments in NSW



3.1 The mix of decision-making models in NSW laws

It is important, with respect to the models of decision-making that were discussed in section 2, to note that NSW law employs both the best interests test and substituted judgment in its legal architecture. Variations and combinations of both models will be described in the laws in this section. Importantly, reference to supported decision-making and the rights, will and preferences of the person with incapacity is completely absent. As discussed in section 3.4, NSW has attempted to introduce supported decision-making via policy, rather than legal reform.

The mixture of best interests components and substituted judgment can be traced throughout both the *Guardianship Act 1987* (NSW) and the *Powers of Attorney Act 2003* (NSW). The Guardianship Act

is based on 'general' governing principles that are outlined in section 4 of the Act (Box 5). All substitute decision-makers under the Act must exercise their powers in light of these principles.

Box 5: Principles of the NSW Guardianship Act⁴⁰

It is the duty of everyone exercising functions under this Act with respect to persons who have disabilities to observe the following principles--

- (a) the welfare and interests of such persons should be given paramount consideration,
- (b) the freedom of decision and freedom of action of such persons should be restricted as little as possible,
- (c) such persons should be encouraged, as far as possible, to live a normal life in the community,
- (d) the views of such persons in relation to the exercise of those functions should be taken into consideration,
- (e) the importance of preserving the family relationships and the cultural and linguistic environments of such persons should be recognised,
- (f) such persons should be encouraged, as far as possible, to be self-reliant in matters relating to their personal, domestic and financial affairs,
- (g) such persons should be protected from neglect, abuse and exploitation,
- (h) the community should be encouraged to apply and promote these principles.

The first principle in Box 5 clearly states that the welfare and interests of the person must be given paramount consideration. This is arguably a reference to the best interests test. Other principles reflect concerns with substituted judgment such as the requirement of decision-makers to consider the views of the person who is incapacitated. 41 'Views' are not defined in legislation. In some decisions from other Australian tribunals, 'views' have been taken to include the expressed opinions and stated desires of the incapacitated person. 42 In other cases, it has been decided that 'views' can be more generally expressed to include the person's general values and preferences, such as, for example, a broad desire to continue living independently in their home. 43 Importantly, the views of the person are not determinative. Nor are they the only principle to consider, leaving us with a mix of best interests and substituted judgment factors.

Supported decision-making is not discussed in the NSW legislation. The laws do not require a person to be provided with support to exercise their capacity. Nor do they require that the will and preferences of a person be given precedence in decision-making. This is despite the

⁴⁰ Guardianship Act 1987 (NSW), s 4.

⁴¹ Guardianship Act 1987 (NSW), s 4(d). 42 Matter of Dylan (Guardianship) [2021] ACAT 91; Re SCT [2020] NTCAT 10.

⁴³ Matter of Jane (Guardianship) [2019] ACAT 18.

recommendations of a NSW parliamentary committee in 2010⁴⁴ and the NSW Law Reform Commission (NSWLRC) in 2018 (see <u>section 3.4</u>).⁴⁵

3.2 Decision-making when a person living with dementia has capacity

If a person has an earlier diagnosis of dementia they may still have the capacity to make decisions about their life, including important financial and property decisions, lifestyle and other healthcare planning, and advance health directives.

3.2.1 Financial and property planning

When a person living with dementia has capacity they may appoint an *enduring attorney* to make financial and property decisions for them in an *enduring power of attorney*. Enduring powers of attorney must be created in writing and signed by both the principal (the person living with dementia) and the attorney (the decision-maker).

Enduring powers of attorney usually become operative after they have been signed but the instrument may specify another time, such as when the principal becomes incapacitated. ⁴⁶ An enduring power of attorney continues to be effective after the principal loses mental capacity.

The appointed attorney may be granted powers in the instrument to manage the person's financial affairs, including management of their assets and accounts. The appointment of an enduring power of attorney helps to protect the estates of people living with dementia as it allows for a trusted person to be chosen to manage their affairs when they become incapacitated.

Attorneys must make decisions in accordance with the principal's best interests and with reasonable diligence and honesty, except as expressly provided for in the appointing instrument. ⁴⁷ This includes requirements for keeping separate financial accounts and keeping records of the principal's money and property.

Both the Supreme Court and the NSW Civil and Administrative Tribunal (NCAT) have the power to supervise attorneys and intervene if they believe the attorney has breached their obligations to manage the person's financial affairs. ⁴⁸ For example, the Supreme Court has the power to confirm the powers that an attorney has when the principal is no longer able to communicate and it is in the principal's best interests for a power to be confirmed. ⁴⁹

3.2.2 Lifestyle and healthcare planning

When a person living with dementia has capacity they may appoint one or more *enduring guardians* to make lifestyle and healthcare decisions for them when they lack capacity. An enduring guardian

⁴⁴ Legislative Council Standing Committee on Social Issues, <u>Substitute decision-making for people lacking capacity</u>, Parliament of NSW, February 2010.

⁴⁵ New South Wales Law Reform Commission, Report 145 - Review of the Guardianship Act 1987, May 2018.

⁴⁶ Powers of Attorney Regulation 2024 (NSW), cl 4. See *GFN* [2021] NSWCATGD 7; *EB v GB* (No 2) [2022] NSWSC 1011; *LNN* [2014] NSWCATGD 50.

⁴⁷ ZMQ v ZMR [2020] NSWCATAP 25; OBQ [2020] NSWCATGD 59; ZND v ZNE [2020] NSWCATAP 34.

⁴⁸ Powers of Attorney Act 2003 (NSW), s 33. See ZND v ZNE [2020] NSWCATAP 34.

⁴⁹ Powers of Attorney Act 2003 (NSW), s 31. See Re Goulder [2005] NSWSC 1116.

may be appointed by a person with capacity to make lifestyle and healthcare decisions for them when they become 'totally or partially incapable of managing their person.' ⁵⁰

Enduring guardians may be given power to make lifestyle and healthcare decisions in the instrument, including, but not limited to, decisions concerning:

- Where the person should live
- What health care the person should receive
- What other kinds of personal services the person should receive.⁵¹

The instrument may limit or exclude any of these functions and the enduring guardian also has the power to perform other ancillary tasks that are necessary to give effect to their functions.⁵²

Enduring guardians must make decisions that align with the general principles of the Guardianship Act (Box 5), with the welfare and interests of the person living with dementia to be given paramount consideration.

Both the Supreme Court and the NCAT have powers to review, confirm, vary or revoke the appointment of an enduring guardian, if it is in the best interests of the person living with dementia.⁵³

3.2.3 Advance health directives

If a person living with dementia has capacity they may make an *advance health directive* regarding their healthcare. Advance health directives usually take the form of refusals of life-sustaining treatment. They are particularly helpful for people who have strongly held beliefs about kinds of treatment and for people who have been diagnosed with chronic or terminal conditions where the treatment pathways are well known and where good evidence can be provided about the kinds of decisions that will have to be made into the future. If a person living with dementia has had an early diagnosis they may find an advance health directive to be a useful way of making decisions about their healthcare.

A person living with dementia may signal their consent to treatments as well, but they cannot demand treatments using a directive.⁵⁴ Treatments will only be provided in accordance with the directive when health practitioners believe that they should be offered.

Advance health directives are recognised in the common law of NSW. 55 There is no legislative form of advance directive in NSW, but there is a precedent provided by the NSW Ministry of Health. 56

⁵⁰ Guardianship Act 1987 (NSW), s 6E.

⁵¹ EB v GB (No 2) [2022] NSWSC 10113; Green v Green [2024] NSWSC 14424; XZG [2021] NSWCATGD 265; HJC [2018] NSWCATGD 7.

⁵² Guardianship Act 1987 (NSW), s 6F.

⁵³ Guardianship Act 1987 (NSW), s 6K. See YKO v YKS [2025] NSWCATAP 29; IF v IG [2004] NSWADTAP 3, [20].

⁵⁴ R (on the application of Burke) v General Medical Council (2004) 79 BMLR 126.

⁵⁵ Re JS [2014] NSWSC 302.

⁵⁶ NSW Ministry of Health, <u>Making an Advance Care Directive - form and information booklet</u>, 15 December 2023, accessed 20 September 2025.

Advance directives will apply where (see Box 6):

- The person making the directive had capacity at the time it was made
- The person was not under the undue influence of other people at the time it was made
- The advance directive applies to the circumstances that have arisen.⁵⁷

Box 6: Case example of an advance health directive

In *Hunter and New England Area Health Service v* A⁵⁸, Mr A was a Jehovah's Witness who had completed an advance health directive in which he had indicated his wish not to be given 'kidney dialysis'. In June 2009, Mr A was admitted to the hospital suffering septic shock. His kidneys failed and he was being kept alive on a ventilator and dialysis machine. He could no longer express his wishes concerning treatment.

The Supreme Court of New South Wales upheld Mr A's common law right to refuse treatment using a directive. NSW does not have legislation recognising the validity of advance health directives. McDougall J found that, even though there were no express provisions for advance health directives in the *Guardianship Act 1987* (NSW), s 33 of the Act recognised the importance of the patient's previously expressed decisions regarding treatment, and those decisions were binding on the healthcare provider.

3.3 Decision-making when a person living with dementia has lost capacity

If a person has lost capacity and they have not made an advance health directive or appointed enduring attorneys and/or guardians, then surrogate decision-makers may be appointed for them by NCAT or the Supreme Court. These surrogate decision-makers must act in accordance with the general principles of the Guardianship Act. NSW legislation also provides mechanisms for consent to medical treatment in cases where a person lacks capacity and has no formal decision-maker (see section 3.3.3).⁵⁹

3.3.1 Financial and property decisions

Financial managers may be appointed for a person living with dementia by NCAT or the Supreme Court. Financial managers make decisions regarding their property and accounts. NCAT may appoint a financial manager only if it is satisfied that:

- The person is not capable of managing those affairs
- There is a need for another person to manage those affairs on the person's behalf

 ⁵⁷ C Stewart, Advance Care Directives, in S Field, K Williams, C Sappideen (eds), *Elder Law: A Guide to Working with Older Australians*, Federation Press, 2018; C Stewart, <u>Advance Directives, the Right to Die and the Common Law: Recent Problems with Blood Transfusions</u>, *Melbourne University Law Review*, 1999, 23: 161-183.
 ⁵⁸ (2009) 74 NSWLR 88.

⁵⁹ Guardianship Act 1987 (NSW), Part 5.

It is in the person's best interests that the order be made. 60

Financial managers must act with the welfare and interests of the person under management as the paramount consideration to ensure that all decisions made advance the interests and quality of life of the protected person. 61 This normally requires a financial manager to consult with the person under management, their family, carers, and relevant professionals to ensure informed decisionmaking.62

3.3.2 Lifestyle and healthcare decisions

Guardians may be appointed by NCAT or the Supreme Court when a person is in 'need of a quardian.'63 In NSW the legislation defines a 'person in need of a quardian' as 'a person who, because of a disability, is totally or partially incapable of managing his or her person'. 64 The definition of 'disability' includes someone who is 'of advanced age', and by reason of the disability (whatever the source of this) the person requires 'supervision or social habilitation.'65

The primary function of quardians is to make lifestyle and healthcare decisions. A quardian usually has the power to make the same kinds of decisions that could have been made by the person under guardianship when they had mental capacity. 66 However, NCAT and the Supreme Court may make orders for the appointment of a *limited quardian* where the quardian's power to make decisions is restricted and must be reviewed within a period of time (usually 3 years). A quardian may be granted powers over where a person shall live, who can they have access to and what medical treatments they may receive. A guardian who has been granted a healthcare decision-making function has the right to make end-of-life decisions for the person under quardianship. 67

3.3.3 Healthcare decision-making beyond enduring guardianship and guardianship

Healthcare decision-making for people living with dementia can be complex as decisions will often need to made about what kinds of interventions are appropriate when a person is living with advanced dementia and nearing the end of their life. For example, questions can arise regarding:

- Withholding life-sustaining treatments such as artificial nutrition and hydration, 68 antibiotics, 69 ventilatory support 70
- Whether medical devices such as pacemakers and implantable cardioverter defibrillators should be employed or maintained⁷¹

⁶⁰ Guardianship Act 1987 (NSW), s 25G. See YKV v YJI [2025] NSWCATAP 96.

⁶¹ PNH [2016] NSWCATGD 76.

⁶² HCN [2020] NSWCATGD 874; UCC [2015] NSWCATGD 505; AOS v NSW Trustee and Guardian [2013] NSWADTAP 336; FND [2015] NSWCATGD 557; PZD [2019] NSWCATGD 31.

⁶³ XZG [2021] NSWCATGD 264; IKJ [2021] NSWCATGD 275; HJC [2018] NSWCATGD 7.

^{64 &}lt;u>Guardianship Act 1987</u> (NSW), <u>s 3(1)(c)</u>.

⁶⁵ Guardianship Act 1987 (NSW), s 3(2). See for example, P v NSW Trustee and Guardian [2015] NSWSC 579, [303]. ⁶⁶ Guardianship Act 1987 (NSW), s 21(2A).

⁶⁷ FI v Public Guardian [2008] NSWADT 263.

⁶⁸ Re HG [2006] QGAAT 26; EK (Guardianship) [2005] VCAT 2520; Korp (Guardianship) [2005] VCAT; Re MC [2003] QGAAT 13; Re BWV [2003] VSC 173; Re TM [2002] QGAAT 1.

⁶⁹ XEX (Guardianship) [2023] VCAT 951; FZQ [2021] NSWCATGD 33.

⁷⁰ AL [2017] WASAT 91.

⁷¹ CK [2025] WASAT 27; KK [2024] WASAT 60.

- The provision of palliative care 72
- Whether cardiopulmonary resuscitation should be conducted.⁷³

Part 5 of the Guardianship Act provides a scheme for medical and dental treatment being consented to by substitute decision-makers beyond those powers bestowed on enduring guardians and guardians. The primary objectives of Part 5 are to ensure that individuals are *not deprived of necessary medical or dental treatment* merely because they lack the capacity to consent and to ensure that any treatment carried out is for the purpose of *promoting and maintaining their health and well-being*.⁷⁴

Part 5 of the Act includes the concept of a *person responsible*, who may be an enduring guardian, a guardian, a spouse, a de facto spouse, a carer, or a close friend or relative, in that order of hierarchy.⁷⁵

Under the Act consent and decision-making requirements vary depending on the nature of the medical treatment:

- Special treatments such as those that are likely to render a person infertile or that are new
 and have not yet gained the support of a substantial number of doctors in the area of
 practice can only be consented to by NCAT
- Clinical trials must be approved by NCAT before they start enrolling subjects who are incapacitated⁷⁶
- Persons responsible can consent to major treatment such general anaesthetics, simple sedation, and treatments that are likely to impair a patient's ability to chew food
- Persons responsible can also consent to other minor treatments
- Major treatment can be given without consent in certain circumstances, including if it is urgent and necessary to save the patient's life⁷⁷
- Minor treatment may be carried out without consent if there is no available person responsible to give consent and the patient does not object to the treatment.⁷⁸

⁷² DBQ [2024] NSWCATGD 24; OC (Application for Administration) [2024] TASCAT 86; XEX (Guardianship) [2024] VCAT 26.

⁷³ DBQ [2024] NSWCATGD 24; NDB [2024] WASAT 34; FNX [2021] NSWCATGD 4; JFL [2020] NSWCATGD 32.

⁷⁴ Guardianship Act 1987 (NSW), s 32.

⁷⁵ Guardianship Act 1987 (NSW), s 33A.

⁷⁶ Guardianship Act 1987 (NSW), <u>s 45AA</u>. See Application for approval for adults unable to consent to their own treatment to participate in a clinical trial (ADRENAL Trial) [2015] NSWCATGD 23. See also, S Then, J Chesterman, Y Matsuyama, <u>Supporting the Involvement of Adults with Cognitive Disabilities in Research: The Need for Reform</u>. *Journal of Law and Medicine*, 2023, 30(2): 459-471, doi: 10.1016/j.ijlp.2018.09.001.

⁷⁷ Guardianship Act 1987 (NSW), s 37.

⁷⁸ Guardianship Act 1987 (NSW), s 37.

Persons responsible cannot consent to limitations of treatment (such as withholding artificial nutrition and hydration) and such decisions need to be made by a guardian with power to make healthcare decisions (see <u>section 3.3.2</u>).⁷⁹

3.4 Supported decision-making in NSW

The analysis in sections 3.2 and 3.3 examines how NSW employs a mixture of best interest factors with substituted judgment in the legal frameworks for decision-making for people living with dementia. Notably, references to the CRPD and supported decision-making do not feature at all in this legal framework. This is primarily because, while Australia is a signatory to the CRPD, international conventions do not become part of Australian domestic law until they are enacted into legislation. To date the NSW government has not introduced reforms that will bring the guardianship laws into compliance with the CRPD.

It may be argued that the principles of the Guardianship Act align with aspects of the CRPD such as the principle that the 'Freedom of decision and freedom of action of such persons should be restricted as little as possible' and the principle that 'Such persons should be encouraged, as far as possible, to live a normal life in the community'. Both these principles allude to the importance of autonomy that accords with the CRPD. Similarly, the principle that 'The views of such persons in relation to the exercise of those functions should be taken into consideration' is related to the CRPD's requirement to respect the 'will and preferences' of a person with a disability. However, such allusions are a far cry from implementation of the CRPD as the Guardianship Act's principles still have the welfare of the person as the paramount consideration in section 4 and this is at odds with the 'rights, will and preferences' approach that is fundamental to supported decision-making.

3.4.1 Law reform recommendations

NSW has had 2 major reviews of how NSW law might be brought into alignment with the CRPD. The NSW Legislative Council Standing Committee on Social Issues prepared a report on *Substitute decision-making for people lacking capacity* in 2010 that made 2 recommendations:

Recommendation 4

That the NSW Government pursue an amendment to NSW legislation in which the issue of capacity in relation to decision-making is raised, including but not limited to the Guardianship Act 1987 and the NSW Trustee and Guardian Act 2009, to include an explicit statement to the effect that the legislation supports the principle of assisted decision-making.

Recommendation 5

That the NSW Government consider amending NSW legislation in which the issue of capacity in relation to decision-making is raised, including but not limited to the Guardianship Act 1987 and the NSW Trustee and Guardian Act 2009, to provide for the relevant courts and tribunals to make orders for assisted decision-making arrangements and to prescribe the criteria that must be met for such orders to be made. That such consideration address the parameters of assisted decision-making, in particular

⁷⁹ FI v Public Guardian [2008] NSW ADT 263 at [40]; ZXO v Public Guardian [2022] NSWCATAP 260; QZS [2020] NSWCATGD 41; DBQ [2024] NSWCATGD 24; ZXO v Public Guardian [2022] NSWCATAP 260; QZS [2020] NSWCATGD 41; DBQ [2024] NSWCATGD 24.

the limit at which the assisting decision-maker's obligation to prevent harm overrides their responsibility to assist.80

Neither of these recommendations have been implemented but the NSW government did refer these matters for consideration to the New South Wales Law Reform Commission (NSWLRC). In 2018 the NSWLRC reviewed the state's guardianship laws. The NSWLRC found that the current guardianship laws no longer reflected 'the social, legal and policy environments that surround it'. 81 The NSWLRC designed a new Act – the Assisted Decision-Making Act. This proposed Act was designed to increase compliance with the CPRD by shifting the law towards the promotion of the 'will and preferences of the person in need of assistance'. As part of this approach, the NSWLRC recommended using terms such as 'assisted decision-making' and appointed 'representatives' to replace 'guardianship,' 'enduring guardianship' and 'powers of attorney.' The NSWLRC recommended keeping the capacity test (referred to as 'decision-making ability') but said that it should be more clearly articulated. 82

The proposed Act created a new process for the appointment of 'supporters' for people with disabilities. The NSWLRC also recommended that NCAT be given powers to make support orders with the consent of the person being supported. 83 The supporter's role would be to access or collect information that is relevant to decisions affecting the person needing support, and to assist them in communicating decisions. 84

The NSWLRC also recommended the creation of 2 new kinds of formal substitute decision-making for people who lack capacity, namely, an *enduring representative* (chosen by the person prior to incapacity to make health, personal and financial decisions, to replace enduring guardians and enduring powers of attorney), and, a *representative* (chosen by a tribunal to replace guardians and financial managers). Both these decision-makers (and anyone else exercising functions under the Act) would be required to approach all decisions on the basis of giving effect to the person's will and preferences. If these cannot be determined, all decision-makers should then be guided by an assessment of what the person's will and preferences would most likely be. The will and preferences may be determined by examining the person's previously expressed will and preferences and by consulting people who have a genuine and ongoing relationship with the person and who may be aware of the person's will and preferences.

As at September 2025 the NSWLRC's proposed *Assisted Decision-making Act* had not been adopted. A NSW Government Guardianship Reform Working Group has re-examined the issue of supported decision making as a response to the Disability Royal Commission and its advice was submitted to the Attorney General in late 2024.⁸⁷ In a budget estimates hearing in August 2025 the

⁸⁰ Legislative Council Standing Committee on Social Issues, <u>Substitute decision-making for people lacking capacity</u>, Parliament of NSW, February 2010.

⁸¹ New South Wales Law Reform Commission, Report 145 - Review of the Guardianship Act 1987, May 2018, xxi, [0.7].

⁸² New South Wales Law Reform Commission, Report 145 - Review of the Guardianship Act 1987, May 2018, Rec 6.1.

⁸³ New South Wales Law Reform Commission, Report 145 - Review of the Guardianship Act 1987, May 2018, Rec 7.7.

⁸⁴ New South Wales Law Reform Commission, Report 145 - Review of the Guardianship Act 1987, May 2018, Rec 7.12.

⁸⁵ New South Wales Law Reform Commission, Report 145 - Review of the Guardianship Act 1987, May 2018, Rec 8.1, Rec 9.1.

⁸⁶ New South Wales Law Reform Commission, Report 145 - Review of the Guardianship Act 1987, May 2018, Rec 5.4.

⁸⁷ New South Wales Government, NSW Government Response to the Disability Royal Commission, 31 July 2024.

Attorney General indicated that the government continues to give consideration to recommended reforms.88

3.4.2 Policy implementation

At the policy level, changes have been made to the operation of the NSW Public Trustee and Guardian that bring its decision-making processes into line with the CRPD. These changes appear to have been partly a response to the My Rights Matter Project, a two-year project run by the Council for Intellectual Disability that aimed to raise awareness of supported decision-making. 89 The website for the NSW Public Trustee and Guardian states very clearly that people with disabilities should be provided with supported decision-making, and this is repeated in the NSW Public Trustee and Guardian's policy on decision-making. 90 The Public Guardian also has an information sheet titled Supported Decision Making Information for family and friends, in which it is recognised that supported decision-making is a human right. 91

The NSW Public Trustee and Guardian is also a member of the Australian Guardianship and Administration Council (AGAC). AGAC has had national guidelines for both public guardianship and financial managers for 25 years. 92 These require that policies and processes are shaped by the CRPD and that the staff in public quardianship roles will adopt supported decision-making in their practice.

AGAC also has policies and guidelines for 'maximising' the participation of the person in proceedings. 93 These national guidelines arose in response to report recommendations from the Australian Law Reform Commission discussed in section 4.1 and provide standards for the management of proceedings in guardianship to maximise the chance for high-quality participation of the person subject to proceedings.

3.5 Conclusions

It is hard to judge how much supported decision-making policies in NSW have penetrated into the governance arrangements for decision-making for people living with dementia. There is some evidence in decisions of NCAT that the tribunal is aware of supported decision-making and is in favour of it being employed for people who may have impaired capacity, but that evidence is not strong. 94 Nor should we overstate the influence of the national guidelines from the AGAC. 95 The policies and quidelines are not binding on tribunals and they do not override the legal requirements

⁸⁸ Legislative Council Portfolio Committee No 5. (Justice and Communities), Examination of proposed expenditure for the portfolio area Attorney General, NSW Parliament, August 2025.

⁸⁹ C Bigby, et al., Evaluation of My Rights Matter: A program to change understanding, skills and policy about supported decision making. La Trobe University Report, September 2024.

⁹⁰ New South Wales Government, Guardianship Orders, n.d, accessed 20 September 2025. See NSW Public Trustee and Guardian, Policy: Decision-making, 1 April 2022, accessed 20 September 2025.

⁹¹ NSW Public Trustee and Guardian, Public Guardian: Supported Decision Making, April 2024, accessed 20 September 2025.

⁹² Australian Guardianship and Administration Council, National Public Guardianship Guidelines 2025, accessed 20 September 2025; Australian Guardianship and Administration Council, National Guidelines for Financial Managers 2024, October 2024, accessed 20 September 2025.

⁹³ Australian Guardianship and Administration Council, <u>Maximising the participation of the Person in guardianship</u> proceedings 2019, 20 June 2019, accessed 20 September 2025.

⁹⁴ See EKD [2024] NSWCATGD 22.

⁹⁵ C Stewart, Capacity, Participation and Values in Australian Guardianship Laws, in C Kong, et al. (eds), Capacity, Participation and Values in Comparative Legal Perspective, Bristol University Press, 2023.

in NSW. A search of the decisions of tribunals across Australia shows that the AGAC guidelines have been referenced only once in hundreds of cases.⁹⁶

While the policy positioning of the NSW Public Trustee and Guardian represents a commitment by the guardianship authorities in NSW to the CRPD, the policy position remains at odds with the express legislative provisions. If this were to change, what kinds of changes are possible and how would those changes work? This is examined in the next section.

⁹⁶ ZQB v ZPV [2020] NSWCATAP 274, [29].

4. The implementation of supported decision-making in other Australian jurisdictions

4.1 A short history of CRPD reforms in Australia

Australia's regulatory response to the ratification of the CRPD has been described as 'glacial.'97 This is despite quite a lot of law reform activity in the last 15 years. All of Australia's jurisdictions barring the Northern Territory have undergone one or more law reform inquiries into guardianship laws. 98 Western Australia's law reform review into guardianship laws is ongoing as at September 2025. 99 Additionally, the Australian government initiated 2 royal commissions which recommended major reforms to aged care and the National Disability Insurance Scheme (NDIS) that would bring these schemes in line with the CRPD. 100

Arguably the most important law reform inquiry was that performed by the Australian Law Reform Commission (ALRC). In 2014, the CRPD was the subject of the ALRC Report on Equality, Capacity and Disability in Commonwealth Laws (2014) (the ALRC report). A large concern of the ALRC report was the concepts of guardianship and substituted decision-making. The ALRC report recommended a set of national decision-making principles that aimed to increase the amount of supported decision-making for people with a disability (Box 7).

⁹⁷ T Carney, S Then, C Sinclair, A New Aged Care Act: Progress in Implementing A Supported Decision-Making Approach in Australia's Federation? UNSW Law Journal Forum, 2024, 1:1-19; T Carney, Prioritising Supported Decision-Making: Running on Empty or a Basis for Glacial-to-Steady Progress?, Laws, 2017, 6(18): 1.

⁹⁸ Queensland law Reform Commission, <u>A Review of Queensland's Guardianship Laws</u>, Report No 67, September 2010; Australian Capital Territory Law Reform Advisory Council, <u>Final Report into the Guardianship and Management of Property Act 1991 (Guardianship Report)</u>, 2016; Tasmanian Law Reform Institute, <u>Review of the Guardianship and Administration Act 1995 (Tas)</u>, Report 26, 2018; South Australian Law Reform Institute, <u>The Need for New Solutions? Establishing Legal Frameworks for Supported Decision-Making in South Australia</u>, Report 21, June 2025.

⁹⁹ Law Reform Commission of Western Australia, <u>Project 114 Guardianship and Administration Act 1990 (WA)</u>, Discussion Paper, Volume 1, December 2024.

¹⁰⁰ Royal Commission into Aged Care Quality and Safety, *Final Report: Care, Dignity and Respect*, Volume 1 Summary and Recommendations, 2021, Recommendation 3(iii).

Box 7: The ALRC National Decision-Making Principles¹⁰¹

Principle 1: The equal right to make decisions

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

Principle 2: Support

Persons who require support in decision-making must be provided with access to 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 persons who may require decision-making support must direct decisions that affect their lives.

Principle 4: Safeguards

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

The ALRC recommended that these principles be used to guide law reform in other Australian jurisdictions. 102 Recommendations related to the incorporation of supported decision-making into Commonwealth laws, with the broad approach that supported decision-making should be introduced into relevant Commonwealth laws and legal frameworks in a form consistent with the national decision-making principles. They also recommended that Commonwealth laws and legal frameworks should include the concept of a supporter and reflect the national decision-making principles in providing that:

- (a) a person who requires decision-making support should be able to choose to be assisted by a supporter, and to cease being supported at any time;
- (b) where a supporter is chosen, ultimate decision-making authority remains with the person who requires decision-making support; and
- (c) supported decisions should be recognised as the decisions of the person who required decision-making support. 103

The ALRC recommended that supporters be required to:

- (a) support the person to make decisions;
- (b) support the person to express their will and preferences in making decisions;

¹⁰¹ Australian Law Reform Commission, <u>Equality, Capacity and Disability in Commonwealth Laws</u>, Report 124, August 2014, p. 64

¹⁰² Australian Law Reform Commission, <u>Equality, Capacity and Disability in Commonwealth Laws</u>, Report 124, August 2014, p. 11

¹⁰³ Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report 124, August 2014, p101.

- (c) act in a manner promoting the personal, social, financial, and cultural wellbeing of the person;
- (d) act honestly, diligently and in good faith;
- (e) support the person to consult, as they wish, with existing appointees, family members, carers and other significant people in their life in making decisions; and
- (f) assist the person to develop their own decision-making ability. 104

These suggestions for reform have been followed by all the law reform inquiries since but the implementation of the reforms into legislation has been patchy. To date, Victoria has made sweeping changes, the ACT, Northern Territory, Queensland and Tasmania have introduced partial reforms, and NSW, Western Australia, and South Australia have yet to introduce any substantial legal changes.

4.2 Soft and hard implementation of the CRPD in state and territory laws

At the risk of generalisation, it is possible to divide the legal changes that have been made into 2 categories – 'soft' and 'hard' implementations of reform.

Both softer and harder versions of reform are characterised by the addition of new guiding principles in guardianship, powers of attorney and healthcare legislation that refer to supported decision-making, and the requirement to consider the rights, will and preferences of the subject person. But in the softer versions, the fundamental structures of capacity testing and the appointment and removal of surrogate decision-makers remain and supported decision-making principles and the rights, will and preferences of people living with dementia are only a factor to consider. ¹⁰⁵

To illustrate both the Queensland *Guardianship and Administration Act 2000* (Qld) and the *Powers of Attorney Act 1998* (Qld), have the following general principles:

8 Maximising an adult's participation in decision-making

- (1) An adult's right to participate, to the greatest extent practicable, in decisions affecting the adult's life must be recognised and taken into account.
- (2) An adult must be given the support and access to information necessary to enable the adult to make or participate in decisions affecting the adult's life.
- (3) An adult must be given the support necessary to enable the adult to communicate the adult's decisions.
- (4) To the greatest extent practicable, a person or other entity, in exercising power for a matter for an adult, must seek the adult's views, wishes and preferences.
- (5) An adult's views, wishes and preferences may be expressed orally, in writing or in another way, including, for example, by conduct.
- (6) An adult is not to be treated as unable to make a decision about a matter unless all practicable steps have been taken to provide the adult with the support and access to information necessary to make and communicate a decision.

 ¹⁰⁴ Australian Law Reform Commission, <u>Equality, Capacity and Disability in Commonwealth Laws</u>, Report 124, August 2014, p 14.
 105 Guardianship and Management of Property Act 1991 (ACT), s 4; <u>Advance Personal Planning Act 2013</u> (NT), s 22; <u>Guardianship of Adults Act 2016</u> (NT), s 4; <u>Health Care Decision Making Act 2023</u> (NT), s 18; <u>Guardianship and Administration Act 2000</u> (Qld), <u>Guardianship and Administration Act 1993</u> (SA), s 5.

In these softer reform jurisdictions, the principles are often threaded through decision-making powers. For example in the ACT, when the ACT Civil and Administrative Tribunal is considering appointing a guardian or a financial manager it must consider whether the provision of support to the protected person would allow the person to participate and communicate their own decisions. These softer jurisdictions may also have specific sections that require decision-makers to attempt to provide support to enable the person to make a decision. The section of the person to make a decision.

A harder and more complete law reform process was implemented in Victoria. The Victorian Parliament responded to its law reform inquiry by making new laws including the *Powers of Attorney Act 2014* (Vic), the *Medical Treatment Planning and Decisions Act 2016* (Vic) and the *Guardianship and Administration Act 2019* (Vic). This draft of laws ushered in the most complete implementation of the CRPD in Australia. The regime operates on the principles that expressly apply the CRPD approach. For example, the *Guardianship and Administration Act 2019* (Vic) operates under the following general principles:

- (a) the person should give all practicable and appropriate effect to the represented person's will and preferences, if known;
- (b) if the person is not able to determine the represented person's will and preferences, the person should give effect as far as practicable in the circumstances to what the person believes the represented person's will and preferences are likely to be, based on all the information available, including information obtained by consulting the represented person's relatives, close friends and carers;
- (c) if the person is not able to determine the represented person's likely will and preferences, the
 person should act in a manner which promotes the represented person's personal and social
 wellbeing;
- (d) if the represented person has a companion animal, the person should act in a manner that recognises the importance of the companion animal to the represented person and any benefits the represented person obtains from the companion animal;
- (e) the represented person's will and preferences should only be overridden if it is necessary to do so to prevent serious harm to the represented person. 108

The primary decision-making mechanisms of appointment of guardians and administrators remains in place but they must be appointed after VCAT's consideration of:

- (a) the will and preferences of the proposed represented person (so far as they can be ascertained);
- (b) whether decisions in relation to the personal or financial matter for which the order is sought—
 - (i) may more suitably be made by informal means; or
 - (ii) may reasonably be made through negotiation, mediation or similar means;

108 Guardianship and Administration Act 2019 (Vic), s 9.

¹⁰⁶ Guardianship and Management of Property Act 1991 (ACT), ss 7-8.

¹⁰⁷ Health Care Decision Making Act 2023 (NT), s 17; Advance Care Directives Act 2013 (SA), s 10(d); Guardianship and Administration Act 1995 (Tas), s 26(1)(j), s 57(j); Guardianship and Administration Act 1990 (WA), s 51(2)(c).

- (c) the wishes of any primary carer or relative of the proposed represented person or other person with a direct interest in the application;
- (d) the desirability of preserving existing relationships that are important to the proposed represented person. 109

The new laws also allow for the appointment by VCAT of supportive guardians and supportive administrators who have the power to access the principal's personal information, communicate with others regarding the principal, and to make decisions for the principal which are reasonably necessary to give effect to a supported decision. 110 VCAT can only appoint these decision-makers if the person has capacity, or, is able to be given practicable and appropriate support so that they will have decision-making capacity. 111

The new laws also created *support persons for medical treatment*, who can be appointed by a person to help them make, communicate and give effect to their medical treatment decisions, and to represent their interests in respect of their medical treatment, including when the person does not have decision-making capacity in relation to medical treatment decisions.¹¹²

4.3 Examining the effectiveness of legal implementation of supported decisionmaking

This section examines the evidence on how legal reforms have changed decision-making in 2 key areas: the duty to provide support, and the use of the will and preferences in decision-making. It looks at examples of tribunal decisions involving the duty to support and the requirement to consider the will and preferences of people with disability. The only available data to measure change are the decisions of tribunals like VCAT. This is discussed below.

4.3.1 The duty to provide support to the person living with dementia to regain capacity and participate in decision-making

Some jurisdictions recognised a duty to support the person with disabilities in ways that might help them have capacity, or regain it, for a decision, prior to the introduction of the CRPD. In Western Australia, guardians must exercise their powers 'in such a way as to encourage and assist the represented person to become capable of caring for himself [sic] and of making reasonable judgments in respect of matters relating to his [sic] person.'113 In South Australia an incapacitated person must be allowed to make their own decisions to the extent that they are able, and must be supported to enable them to make their own decisions for as long as possible.¹¹⁴ Queensland legislation states that:

(6) An adult is not to be treated as unable to make a decision about a matter unless all practicable steps have been taken to provide the adult with the support and access to information necessary to make and communicate a decision. ¹¹⁵

¹⁰⁹ Guardianship and Administration Act 2019 (Vic), s 31.

¹¹⁰ Powers of Attorney Act 2014 (Vic), ss 84-90.

¹¹¹ Powers of Attorney Act 2014 (Vic), s 87(2).

¹¹² Medical Treatment Planning and Decisions Act 2016 (Vic), s 31.

¹¹³ Guardianship and Administration Act 1990 (WA), s 51(2)(c).

¹¹⁴ Advance Care Directives Act 2013 (SA), s 10(d).

¹¹⁵ Guardianship and Administration Act 2000 (Old), s 11B, Principle 8(6).

In Victorian legislation that was crafted in response to the CRPD, persons exercising power under the Act should provide appropriate support to enable the person with a disability, 'as far as practicable in the circumstances - to develop the person's decision-making capacity.'¹¹⁶

So far there is little evidence that tribunals are enforcing the obligation to support a person living with dementia to regain capacity and be able to make decisions. ¹¹⁷ The cases overwhelmingly apply the capacity test as a threshold issue but, in cases where the person living with dementia is found to lack capacity, the tribunals do not go on to examine whether the person could be provided with support to regain capacity. ¹¹⁸ This may be because by the time the matter has reached the tribunal stage the person living with dementia has progressed beyond a stage where it is possible to provide support to regain capacity.

Another separate but related concern is the medicalisation of the testing of capacity. Analysis of the Victorian caselaw shows that medical evidence is the primary source of evidence of incapacity. Some authors have been critical of the preeminent role that medical evidence is given in capacity assessment. ¹¹⁹ There are concerns that a purely medical focus may delegate too much authority to a medical approach to what is, essentially, a legal test. ¹²⁰ On the other hand, the role played by independent health professionals is also important to ensure a form of oversight, especially in cases where individual and/or familial claims may be bound up in conflicts of interest. ¹²¹

The best way to navigate the course between these concerns would be to make sure that the expert medical opinion is current and based on actual observations of the person with dementia, rather than reliance on second-hand accounts. ¹²² Secondly, health experts should be employing tests that are related to the legal test of capacity rather than on cognition. Thirdly, as discussed above, it remains important for the tribunals to include the person living with dementia in the proceedings. ¹²³ More could be done in this regard. ¹²⁴ For example in *Matter of Jane (Guardianship)*, ¹²⁵ McCathy PM

¹¹⁶ <u>Guardianship and Administration Act 2019</u> (Vic), s 8.

¹¹⁷ M Blake, People Living with Dementia: What Difference Does Statutory Change Make? A Case Study from Australia, Medical Research Archives, 2025, 13(1), doi: 10.18103/mra.v13i1.6135. See also the discussion in T Carney, From Guardianship to Supported Decision-Making: Still Searching for True North? Journal of Law and Medicine, 2023, 30(1): 70-84. See also WMO (Guardianship) [2023] VCAT 53; ALG (Guardianship) [2023] VCAT 344; VWT (Guardianship) [2023] VCAT 1151; BHP [2024] VCAT 276; QBZ (Guardianship) [2024] VCAT 687; ICV (Guardianship) [2025] VCAT 463; VNR (Guardianship) [2025] VCAT 359. But see CPG (Guardianship) [2025] VCAT 63 and IGD (Guardianship) [2025] VCAT 358 as examples of where VCAT found that support would not help to give a person living with dementia regain their capacity.

¹¹⁸ M Blake, People Living with Dementia: What Difference Does Statutory Change Make? A Case Study from Australia, Medical Research Archives, 2025, 13(1), doi: 10.18103/mra.v13i1.6135.

¹¹⁹ Blake et al, Supported Decision-Making for People Living with Dementia: An Examination of Four Australian Guardianship Laws. *Journal of Law and Medicine*, 2019, 28(2), 389-420.; M Blake, People Living with Dementia: What Difference Does Statutory Change Make? A Case Study from Australia, *Medical Research Archives*, 2025, 13(1), doi: 10.18103/mra.v13i1.6135. 120 GJM [2024] QCAT 166. But see *HLQ* (Guardianship) [2025] VCAT 461, where a solicitor's assessment that a person living with dementia had capacity to execute a power of attorney was overturned on the basis of medical evidence. 121 See *RCF* (Guardianship) [2023] VCAT 893; *ESU* (Guardianship) [2024] VCAT 340; *XEX* (Guardianship) [2024] VCAT 26; *ICV*

⁽Guardianship) [2025] VCAT 463.

122 See QSE (Guardianship) [2024] VCAT 1002, an example of where a doctor's report was rejected for not complying with the requirement to do a face to face assessment (noting that the case was not one involving dementia).

¹²³ See AAB [2025] QCAT 92, where evidence was taken from the person living with dementia, her carers and medical practitioners. See also GJM [2024] QCAT 166 for an example of where capacity is treated as a medical decision but with supporting evidence from relatives.

 ¹²⁴ C Stewart, Capacity, Participation and Values in Australian Guardianship Laws, in C Kong, et al (eds), Capacity, Participation and Values in Comparative Legal Perspective, Bristol University Press, 2023.
 125 [2019] ACAT 18.

was asked to place an elderly woman under guardianship, even though she wished to remain living independently. McCathy PM recognised the importance of hearing directly from the person and said:

This case highlighted a further issue that warrants comment. My prior reading of the reports regarding Jane gave me an impression of an elderly, frail person in the twilight of her life. I could not have been more wrong. Jane strode into the hearing room at a quick pace, unaided, and ahead of Julia and the social workers. Unlike many others who are the subject of a guardianship application from whom comment needs to be carefully and slowly drawn in order to ascertain their views and wishes about the application, Jane was the first to speak at the hearing. She spoke with a strong and articulate voice, quickly engaging in courteous but defiant resistance of the hearing and its purpose.

But for Jane's attendance, I would have had little if any ability to know or appreciate her point of view, and yet the sole purpose of the hearing was to decide whether to make decisions (and, in her view, adverse decisions) regarding her health, welfare, finances and property (at [95]-[96]).

This case highlights the importance of seeing, speaking with and listening to people living with dementia when assessing their capacity. In some cases this has been legislated, for example, in Victoria, there is a legal requirement for the person to attend any hearing in person, unless they do not wish to do so or it is impractical or unreasonable. 126

4.3.2. Placing the will and preferences of the person at the centre of decision-making

There is growing evidence suggesting that when laws place the will and preferences of the person at the centre of decision-making, decision-making for people living with dementia will be more aligned with their wishes.¹²⁷

How are the will and preferences of a person determined? The legislation does not provide much guidance. In Queensland the legislation states that a person's 'views, wishes and preferences may be expressed orally, in writing or in another way, including, for example, by conduct.' Other jurisdictions are silent on the matter. Carney et al have argued that more needs to be done to give guidance on how to determine what a person's will and preferences are. More could also be done to give guidance on how to balance conflicting preferences when a person living with dementia is expressing different views to the ones they had previously held.

Nevertheless, there is a growing jurisprudence on how to assess will and preferences, particularly with respect to decisions about where people living with dementia should reside, 130 who they want as their guardians 131 and who they want as their administrators. 132

¹²⁶ Guardianship and Administration Act 2019 (Vic), ss 29, 165.

¹²⁷ M Blake, <u>People Living with Dementia: What Difference Does Statutory Change Make? A Case Study from Australia, Medical Research Archives</u>, 2025, 13(1), doi: 10.18103/mra.v13i1.6135. But see T Carney, From Guardianship to Supported Decision-Making: Still Searching for True North? *Journal of Law and Medicine*, 2023, 30: 78 who argues that the evidence is less convincing.

¹²⁸ Guardianship and Administration Act 2000 (Qld), s 11B, Principle 8(5).

¹²⁹ T Carney, From Guardianship to Supported Decision-Making: Still Searching for True North? *Journal of Law and Medicine*, 2023, 30: 70-84.

¹³⁰ QBZ (Guardianship) [2024] VCAT 687 (husband appointed as guardian based on will and preferences to live at home); KGW (Guardianship) [2024] VCAT 1091 (no guardian appointed as person was happy with living arrangement at care home).

¹³¹ WMO (Guardianship) [2023] VCAT 53 (sister appointed as guardian based on wills and preferences).

¹³² KXO (Guardianship) [2025] VCAT 172 (friend and guardian appointed as administrator based on wills and preferences).

A good example of how people living with disabilities can be involved in decision-making is *VNR* (*Guardianship*). ¹³³ In this case VCAT spoke with a person living with dementia about her wishes to return to living at home. She wanted to make her own assessments of what services she needed. VNR acknowledged that she needed to ask for more help around the house. VCAT found (based mainly on medical and familial evidence) that VNR lacked capacity and was in need of a guardian to help arrange for services to be provided to VNR when she returned home. Less formal arrangements were considered but a formal decision-maker was necessary to independently communicate and consult with the service providers that VNR needed. VCAT refused to appoint a financial administrator as, despite her dementia, there was no proof that VNR was making poor financial decisions.

Another example comes from *ONJ* (*Guardianship*). ¹³⁴ ONJ was a retired academic who had been diagnosed with Alzheimer's disease in 2021. ONJ wished to live in her home with her partner of 30 years, KAV, but her son and daughter (who had previously been her guardians) wished for her to live in an aged care residence. ONJ very clearly wished to return home to live with KAV. VCAT relied on medical evidence to find that ONJ lacked capacity and required the help of a guardian, rather than an informal arrangement. VCAT then appointed KAV as the guardian on the basis that it reflected the will and preferences of ONJ.

What happens if the person living with dementia is no longer able to communicate their will and preferences? In Victoria, the *Guardianship and Administration Act 2019* (Vic), 135 states that if the decision-maker is not able to determine the represented person's will and preferences, they should give effect as far as practicable in the circumstances to what the person believes the represented person's will and preferences are 'likely to be, based on all the information available, including information obtained by consulting the represented person's relatives, close friends and carers'. Furthermore, if the decision-maker is not able to determine the represented person's likely will and preferences, 'the person should act in a manner which promotes the represented person's personal and social wellbeing.' Section 4 of the Act describes a list of the ways a person's personal and social wellbeing might be promoted, including recognising the inherent dignity of the person and respecting their individuality.

XEX (Guardianship) 136 is a case that illustrates this approach. XEX was an 84 year-old, Italian speaking man living with vascular dementia. He had two sons who were in disagreement about his care. Questions arose as to who should be his guardian and where he should reside. XEX was ambivalent about these choices and VCAT was not able to discern his will and preferences. VCAT decided to appoint the Public Guardian to promote XEX's personal and social wellbeing, given his sons were unable to reach a compromise on the question of where their father should live.

Are there cases where the person's will and preferences should not be followed?¹³⁷ There are jurisdictions that expressly provide for the wishes and values of the person to be overridden in

^{133 [2025]} VCAT 359.

¹³⁴ [2023] VCAT 48.

¹³⁵ Guardianship and Administration Act 2019 (Vic) s 9.

^{136 [2024]} VCAT 26.

¹³⁷ See discussion in Law Reform Commission of Western Australia, <u>Project 114 Guardianship and Administration Act 1990</u> (WA), Discussion Paper, Volume 1, p 100-101.

certain situations. For example, in Victoria, the legislation states that a where a person has a manager or an administrator appointed their will and preferences should only be overridden if it is 'necessary to prevent serious harm to the represented person'. 138 Examples of harm that have been considered serious enough to override a person's will and preference include financial harms 139 and the risk of living alone without support services. 140

 $^{^{138}}$ <u>Guardianship and Administration Act 2019</u> (Vic), s 9. 139 EHV (Guardianship) [2021] VCAT 425 [65].

¹⁴⁰ VDX (Guardianship) [2020] VCAT 1186 [37].

5. The future of supported decisionmaking in NSW?

This section highlights issues with maintaining the current regulatory approach in NSW. A major issue is the impact of Commonwealth laws such as the new *Aged Care Act 2024* (Cth) and the NDIS that have opted to use a supported decision-making framework that is based on the CRPD. If NSW maintains its existing laws, decision-makers in NSW will have 2 separate and competing standards for decision-making to apply in the care and management of people living with dementia.

5.1 Maintaining the present legislation in NSW and continuing to apply supported decision-making to policy and practice

It has been more than 14 years since Australia became a signatory to the CRPD. The NSW approach has been to apply the CRPD to policy and practice but leaving the law unchanged. This choice has the advantage of letting the NSW government watch and observe how other jurisdictions have handled their reform movements.

However, there are concerns with the current NSW approach. One major problem is the recognition that while NSW policies and procedures are CRPD compliant, the law is not. The current approach creates a disjunct between policies based on supported decision-making and a human rights framework that currently has no legal basis in NSW. It is an odd thing for a government agency, the NSW Public Trustee and Guardian, to espouse adherence to human rights that are not technically part of the law. It may also be argued that a decision-maker who adhered strictly to supported decision-making in their duties in NSW is not compliant with their statutory duties to apply the current statutory mix of best interests and substituted judgment in their surrogate decision-making.

The NSW legal position is also possibly at odds with recommendations for reform that have been raised repeatedly by important bodies such as the ALRC, the NSWLRC and the Royal Commission into Aged Care Quality and Safety. 141 Most recently, in 2023, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability made a number of recommendations regarding the need for supported decision-making at a state level. 142 They included recommendations that:

- State and territory guardianship and administration legislation should be reformed to recognise and encourage supported decision-making
- All Australian governments adopt uniform national decision-making principles that include a
 right to make decisions; a presumption of decision-making ability; legal recognition of the
 role of informal supporters and advocates; a right to access the support necessary to

 ¹⁴¹ Australian Law Reform Commission, Equality, Capacity and Disability in Commonwealth Laws, Report 124, August 2014;
 New South Wales Law Reform Commission, Report 145 - Review of the Guardianship Act 1987, May 2018; Royal Commission into Aged Care Quality and Safety, Final Report: Care, Dignity and Respect, Volume 1 Summary and Recommendations, 2021.
 142 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Final Report - Executive summary, Our vision for an inclusive Australia and Recommendations, September 2023. See also, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Roundtable Supported decision-making and guardianship: Proposals for reform, May 2022.

- communicate and participate in decisions and legal rules to ensure decisions should be directed by a person's own will and preferences
- Tribunal practices and processes maximise the participation of people with disability in proceedings
- States and territories ensure the functions of public advocates and public guardians include providing information, education and training on supported decision-making. To complement these efforts, we recommend every state and territory have a statutory body to undertake systemic advocacy to promote supported decision-making.¹⁴³

5.2 Inconsistency between NSW regulation and the Aged Care Act 2024 (Cth)

There is potential for conflict between NSW laws and the new *Aged Care Act 2024* (Cth). ¹⁴⁴ The *Aged Care Act* has the potential to impact the care of nearly every person in NSW living with dementia. Any inconsistency between NSW's regulatory position and the *Aged Care Act* has the potential to create a lot of confusion, leading to poorer decision-making and poorer quality of care for people living with dementia. ¹⁴⁵

The Act will come into law on 1 November 2025. It creates a new rights-based model of aged care. Section 23 of the new Act recognises that:

- (1) An individual has a right to:
 - (a) exercise choice and make decisions that affect the individual's life, including in relation to the following:
 - i. the funded aged care services the individual has been approved to access;
 - ii. how, when and by whom those services are delivered to the individual;
 - iii. the individual's financial affairs and personal possessions; and
 - (b) be supported (if necessary) to make those decisions, and have those decisions respected; and
 - (c) take personal risks, including in pursuit of the individual's quality of life, social participation and intimate and sexual relationships....
- (10) An individual has a right to be supported by an advocate or other person of the individual's choice, including when exercising or seeking to understand the individual's rights in this section, voicing the individual's opinions, making decisions that affect the individual's life and making complaints or giving feedback.

Aged care providers must take reasonable and proportionate steps to act compatibly with these rights. Supporters' under the Act have a duty to support the individual only to the extent necessary for the individual to do the thing, applying the supporter's best endeavours to maintain the ability of the individual to make the individual's own decisions. Agency testing is completely

¹⁴³ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Final Report - Executive summary, Our vision for an inclusive Australia and Recommendations*, September 2023, p 76-80.

¹⁴⁴ A Mackay, L Grenfell, J Debeljak, <u>A New Aged Care Act for Australia? Examining the Royal Commission's Proposal for Human Rights Inclusive Legislation</u>, *UNSW Law Journal*, 2023, 46(3): 836.

¹⁴⁵ T Carney, S Then and C Sinclair, <u>A New Aged Care Act: Progress in Implementing a Supported Decision-Making Approach in Australia's Federation?</u>, *UNSW Law Journal Forum*, 2024, 1:1.

¹⁴⁶ Aged Care Act 2024 (Cth), s 24.

¹⁴⁷ Aged Care Act 2024 (Cth), s 30(2)(c).

absent from the legislation. These standards are very much at odds with the models of decision-making in NSW.

The Aged Care Act recognises the decision-makers that have been appointed in accordance with state and territory legislation. ¹⁴⁸ Formally appointed decision-makers must be registered with the System Governor ¹⁴⁹ (or delegates) as a 'supporter', although the System Governor has the power to refuse registration if the Governor is not satisfied that the decision-maker can comply with the duties of being a supporter under the Act. ¹⁵⁰ The Western Australia Law Reform Commission has pointed out that the requirement for registration means that unregistered decision-makers who have been formally appointed at the state and territory level will have no power to make decisions under the Aged Care Act. ¹⁵¹ This will affect many important functions of decision-making such as deciding where to reside, or who may have access for visitation.

There is great potential for confusion in the application of two very different systems being applied to people living with dementia. The Western Australia Law Reform Commission has said:

...confusion may arise as a result of the differences between the roles, functions and duties of supporters and formal decision-makers. For example:

- A formal decision-maker may be confused about the scope of their role and function as a supporter and may not appreciate the differences between their two roles.
- Under the Aged Care Act, supporters have a duty to act in a manner that promotes the aged care participant's 'will, preferences and personal, cultural and social wellbeing'. This is different to the best interests standard that applies to formal decision-makers appointed under the Act.
- Under the Act, an enduring instrument that appoints more than one formal decision-maker
 may require those substitute decision-makers to act jointly. However, under the Aged Care
 Act, multiple supporters may act jointly and severally. 152

Given that the current laws in Western Australia are very similar to those in NSW, similar conclusions can be drawn about the problems that may arise from the conflict between the NSW position and the new *Aged Care Act*.

5.3 Inconsistency between NSW regulation and the NDIS

A second inconsistency exists between the NSW legislation and the NDIS. The Australian government introduced the NDIS in 2013. The NDIS Act has a number of stated principles for supported decision-making including that:

Reasonable and necessary supports for people with disability should:

¹⁵¹ Law Reform Commission of Western Australia, <u>Project 114 Guardianship and Administration Act 1990 (WA)</u>, Discussion Paper Volume 2, April 2025, p 199.

¹⁴⁸ Aged Care Act 2024 (Cth), s 28(2). See T Carney, S Then and C Sinclair, <u>A New Aged Care Act: Progress in Implementing a Supported Decision-Making Approach in Australia's Federation?</u>, *UNSW Law Journal Forum*, 2024, 1:1.

¹⁴⁹ The 'System Governor' is the Secretary of the Department of Health and Aged Care.

¹⁵⁰ Aged Care Act 2024 (Cth), s 37.

¹⁵² Law Reform Commission of Western Australia, *Project 114 Guardianship and Administration Act 1990 (WA)*, Discussion Paper, Volume 2, April 2025, p 200.

- (a) support people with disability to pursue their goals and maximise their independence; and
- (b) support people with disability to live independently and to be included in the community as fully participating citizens; and
- (c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment. 153

Additionally, when decisions are being made by others:

- (a) people with disability should be involved in decision making processes that affect them, and where possible make decisions for themselves;
- (b) people with disability should be encouraged to engage in the life of the community;
- (c) the judgements and decisions that people with disability would have made for themselves should be taken into account.... 154

Chapter 3 of the NDIS Act is geared towards maximising the participation of people with disability. Section 17A(1) states that people with a disability are assumed, so far as is reasonable in the circumstances, to have capacity to determine their own best interests and make decisions that affect their own lives. The Act also mandates that people with disability will be supported in their dealings and communications so that their capacity to exercise choice and control is maximised. 155

People who have been diagnosed with dementia before the age of 65 are eligible for support under the NDIS. ¹⁵⁶ Diagnosis of dementia before 65 years is not as common as diagnosis after 65 years, and so the number of people living with dementia and also receiving benefits under the NDIS may be small compared to the number of people being diagnosed after 65. Nevertheless, there will be significant numbers of people who are living with dementia accessing the NDIS. Substitute decision-makers for those people in NSW may have to make decisions under the NDIS using different models of decision-making, with the potential for confusion and poor decision-making. ¹⁵⁷

¹⁵³ National Disability Insurance Scheme Act 2013 (Cth), s 4(11).

¹⁵⁴ National Disability Insurance Scheme Act 2013 (Cth), s 5.

¹⁵⁵ National Disability Insurance Scheme Act 2013 (Cth), s 17A(2).

¹⁵⁶ Dementia Australia, National Disability Insurance Scheme support, 1 April 2025, accessed 25 September 2025.

¹⁵⁷ T Carney, S Then and C Sinclair, <u>A New Aged Care Act: Progress in Implementing a Supported Decision-Making Approach in Australia's Federation?</u>, *UNSW Law Journal Forum*, 2024, 1:1.

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has spent time living on Dunghutti Country and is currently living in Western Sydney on Darug Country with her husband and son.

