

Cognitive Decline Partnership Centre Activity 24 Project Team

Submission to the NSW Law Reform Commission Inquiry into the Guardianship Act 1987

Dear Commissioner

Thank you for the opportunity to make a submission to this Inquiry. We write in our capacity as a team of academic researchers, practitioners and consumer representatives involved in a Cognitive Decline Partnership Centre funded research project. This research team includes members with expertise in law, medicine, psychology, aged care service provision and policy development. The project is investigating community and professional views on supported decision-making, as a potential way of facilitating greater involvement in decision-making and advance care planning by people with dementia and their care-partners.

Terms of Reference:

Considering the scope of this research project, and the fact that our work is still in its initial stages, we limit our submission to the context of people living with dementia, and within the following Terms of Reference:

- The Report of the 2014 ALRC Equality, Capacity and Disability in Commonwealth Laws
- The UN Convention on the Rights of Persons with Disabilities
- The demographics of NSW and in particular the increase in the ageing population

Within these terms of reference, we are addressing point 5 of the Inquiry:

Whether the language of ‘disability’ is the appropriate conceptual language for the guardianship and financial management regime and to what extent decision-making capacity is more appropriate?

Our submission focuses on the guardianship regime and is concerned with the implications of that regime for the ageing population, specifically those living with dementia. We do so with reference to the norms outlined in the Convention on the Rights of Persons with Disabilities (CRPD) and the decision-making principles enunciated in the ALRC Report on Equality, Capacity and Disability in Commonwealth Laws (ALRC Report).

Dementia can be considered to be a disability under the CRPD, and its particular features raise specific questions about the ability of the guardianship regime to sufficiently support persons with dementia in relation to decisions about their health and lifestyle. At the outset, we note that the CRPD advocates for a ‘social model of disability’.¹ This approach views disability as being caused by an

¹ Paul Harpur, ‘Embracing the new disability rights paradigm: the importance of

interaction between a person's impairment (e.g. cognitive impairment) and society's accommodation (or lack of accommodation) of these impairments.²

Reflecting upon our research, we seek to make a number of points about the current legislation. This research has involved an analysis of the relevant current legislation in Western Australia, South Australia, New South Wales and the Commonwealth together with all published decisions of the Courts and Administrative Tribunals in those jurisdictions from 1 January 2015 to 1 September 2016 which directly relate to the question of the appointment of a guardian for a person living with dementia. This legislation and case law was specifically examined in light of the following four questions, as set out by the ALRC (2014) report and their National Decision-Making Principles:

1. Is there a presumption of capacity and how is incapacity determined?
2. Is there evidence of support arrangements being accepted as an alternative to formal substitute decision-making?
3. How are people's rights, will and preference currently being given effect?
4. What safeguards are in place for the decision-making arrangements?

We also draw from other research which members of the group have been engaged in. In relation to Point 5 of the Inquiry, we make the following observations:

Comparative Analysis of Guardianship Legislation:

1. Currently there are different 'triggers' for the imposition of a guardianship order in these three jurisdictions.
 - a. The NSW legislation states that a guardianship order can be made for any person whom the New South Wales Civil and Administrative Tribunal (NCAT) considers to be a 'person in need of a guardian'.³ In order to be 'a person in need of a guardian' the NCAT must be satisfied that the person is totally or partially incapable of managing his or her person due to a disability.⁴ A person with a disability is further defined as a person who is restricted in one or more major life activities to such an extent that he or she requires supervision or social habilitation as a result of a physical, psychological, sensory or intellectual disability, advanced age, mental illness, or any other disability.⁵
 - b. The WA legislation requires that a person be judged to lack decision-making capacity, before a guardianship order can be imposed. Decision-making capacity is defined from a predominantly 'functional' perspective, with a statutory presumption of capacity.⁶
 - c. The SA Guardianship legislation requires that a person be identified as having a "mental incapacity", which is further defined with reference to the

the Convention on the Rights of Persons with Disabilities' (2012) 27 *Disability and Society* 1, 3.

² Michael Oliver, *The Politics of Disablement: A Sociological Approach* (Macmillan, 1990), 11.

³ *Guardianship Act 1987* (NSW), s 14 (1).

⁴ *Guardianship Act 1987* (NSW), s 3 (1).

⁵ *Guardianship Act 1987* (NSW), s 3 (2).

⁶ *Guardianship and Administration Act 1990* (WA), s 43 (1)(b)

person's functional abilities, with the necessity that they have "an impairment... of brain or mind" or are "unable to communicate his or her intentions".⁷

2. All of these jurisdictions include an additional requirement that the person is 'in need of a guardian', which we refer to as the 'principle of necessity'.
3. Within the jurisdictions that require identification of a disability prior to making a Guardianship order, there are also different definitions of what constitutes disability. Currently in NSW a person can be identified as being a person who may be 'in need of a guardian' on the basis of advanced age. While we acknowledge that previous judgements have taken a circumspect interpretation of this clause,⁸ we believe that in the context of an ageing population, increasing numbers of cases will test this provision, with a potential for negative outcomes. Even aside from the context of an ageing population, this is not an appropriate standard for defining disability and is clearly discriminatory.

Analysis of Tribunal Decisions:

Our research into Tribunal decisions in WA and NSW showed a general reliance in both jurisdictions upon medical evidence in order to determine the functional abilities of a person with dementia to demonstrate and exercise his or her capacity. While the medical evidence appeared to be utilised in much the same way in both jurisdictions, in Western Australia where the presumption of capacity is enshrined in the legislation, reference to the presumption of capacity was made in every case. Comparatively, it was only on rare occasions that the NCAT made note of the common law presumption of capacity.

Nevertheless, in both New South Wales and Western Australia, despite the Tribunals being satisfied that a person lacks capacity, it is only where the condition of necessity is also satisfied that a guardianship order will be made. Therefore, the central issues in determining whether or not a guardianship order should be made is whether a person has capacity and is able to exercise that capacity to safeguard their own rights, will and preference, rather than focusing on the reason for a person lacking capacity in the first place. For example, in the Western Australian jurisdiction, one case illustrated that while a person with dementia may have a disability, this may not be a sufficient basis for establishing either a lack of decision-making capacity, or the need for a guardian.⁹ On the other hand, there have also been cases in which entirely transitory conditions,

⁷ *Guardianship and Administration Act 1993* (SA), s 3. However of note is the more recent definition of 'Impaired Decision-Making Capacity' in the *Advance Care Directives Act 2013* (SA), which reinforces the common law position of defining capacity from a functional perspective, and also clarifies that a person is not to be considered to be incapable simply because they cannot understand technical information, can only retain information for a short amount of time, experience fluctuations in their decision-making capacity, or because their decisions may result in an adverse outcome for the person.

⁸ *P v NSW Trustee and Guardian* [2015] NSWSC 579 [290]

⁹ *AQ* [2015] WASAT 139

without the finding of a mental disability, still resulted in an identification of a person lacking decision-making capacity and being in need of a guardian.¹⁰

Despite the definition of disability in the *Guardianship Act 1987* (NSW), s 3(b) being sufficiently broad that it is near impossible to envisage a circumstance in which a person may be deemed to lack capacity, but not satisfy the definition of 'disability', the pre-condition that a person must have a disability before a guardianship order can be made for them is inherently discriminatory and unnecessary.

RECOMMENDATION ONE: That reference to the term 'disability' be removed in relation to the considerations relevant to the pre-conditions for imposition of a guardianship order.¹¹

RECOMMENDATION TWO: That reference to 'advanced age' be removed in relation to the considerations relevant to the pre-conditions for imposition of a guardianship order.

RECOMMENDATION THREE: That a functional test of decision-making capacity replaces the identification of a disability as a pre-condition for imposition of a guardianship order.

We acknowledge the NSW Government's previous response to recommendations to remove reference to disability in the preconditions for imposing guardianship orders, due to concern that people without any disability might come under guardianship jurisdiction inappropriately, simply due to having an eccentric lifestyle or perhaps due to coming from a cultural group with different behavioural norms.¹² We agree that this would be a negative outcome. We also acknowledge previous recommendations (e.g. from the Victorian Law Reform Commission) that maintaining a disability requirement in guardianship legislation constitutes an "objective safeguard" which can be verified using "accepted tests".¹³

We note that Tribunal decision-making does, in a number of cases, show evidence of nuanced understanding of the issues relating to decision-making capacity in dementia. In the decision referred to above, the Tribunal recognised that what appears to be a lack of understanding should not be automatically attributed to the diagnosis of dementia, or equated with lack of capacity.¹⁴ They also give consideration to the man's relationships, family history and personal values, when considering the reasonableness of his decision-making. Hence a

¹⁰ *FH* [2016] WASAT 95 [42]-[47]

¹¹ This is consistent with a similar recommendation made by the Essex Autonomy Project, in respect of the 'diagnostic threshold' embedded in the UK Mental Capacity Act (2005), tethering 'mental incapacity' to "an impairment of, or a disturbance in the functioning of, the mind or brain." See Recommendation 4 in Essex Autonomy Project. 'Achieving CRPD compliance: An Essex Autonomy Project Position Paper', 2016 <http://autonomy.essex.ac.uk/uncrpd>.

¹² NSW Government, *Legislative Council Standing Committee on Social Issues Substitute Decision-Making for People Lacking Capacity: Government Response* (2011) Rec 6.

¹³ Victorian Law Reform Commission, *Guardianship*, Final Report 24 (2012) [12.104]

¹⁴ *AQ* [2015] WASAT 139

person's lack of understanding, in the absence of appropriate support, should not be seen as a criterion for overturning a presumption of decision-making capacity. There is a need to provide support in the form of proactive information and explanation as a precondition to be satisfied prior to a finding of incapacity.

We believe that concerns about inappropriate application of guardianship could be avoided through a carefully worded statutory definition of a functional test of decision-making capacity. This definition should include a presumption of capacity, and provisions that this presumption is not overturned simply on the basis of a diagnosis, or the nature of the person's preferences. On these points, we would commend the principles embedded in the *Advance Care Directives Act SA* (2013),¹⁵ although we acknowledge that considerations may differ to some extent when considering the pre-conditions for imposing guardianship orders.

RECOMMENDATION FOUR: That the definition of decision-making capacity applied as a functional criteria for guardianship imposition be supported by additional provisions, specifying that the presumption of capacity cannot be overturned simply due to the diagnosis of an impairment or disturbance of brain or mind, or the fact that the person's decision-making is unusual or eccentric.

Our research into tribunal decisions and guardianship orders in the context of dementia indicates that tribunals often refer directly to the 'principle of necessity' in imposing a guardianship order. While there is intent to ensure that guardianship orders are imposed only when necessary, it is evident that tribunals struggle to avoid imposing a guardianship order where there is family conflict or 'unworkable situations'. For example, of the 35 relevant decisions reviewed in NSW and WA during 2015-2016, where it was determined that a person lacked capacity, guardianship orders were avoided only in six. In many cases, the tribunal noted that while the person of interest could potentially continue to make decisions with appropriate support, family conflict precluded this.¹⁶

¹⁵ *Advance Care Directives Act 2013* (SA) s 7(2)

¹⁶ *JH [2016] WASAT 20*, [22]-[34] (for past 2 years supported by son to continue living at home. Due to recent deterioration in condition it, JH no longer able to make reasonable judgments. Guardian appointed due to considerable conflict between JH's children making informal decision-making arrangements unworkable); *RR [2015] WASAT 142*, [34]-[35] (spouse acting as informal substituted decision-maker prior to spouse's death); *TLT [2015] NSWCATGD 48*, [78]-[79] (due to family conflict, TLT does not have the necessary support to enable her to exercise her decision-making capacity); *MG [2015] WASAT 50*, [56]-[62], [76] (conflicting medical evidence re. capacity, but due to family conflict informal arrangements were unworkable); *BM [2016] WASAT 79*, [54], [60] (son unofficially acting as substitute decision-maker prior to application – guardian required due to family conflict); *LGM [2016] WASAT 45*, [28]-[44], [99] (GP of opinion that LGM has capacity; however, SAT of the opinion that son had effectively been acting as substitute decision-maker. Given son's history of drug abuse it was not in LGM's best interests for informal arrangements to continue ([83])); *HNI [2016] NSWCATGD 12* (evidence of some specialists that despite her cognitive disability HNI retained capacity to determine where she lives ([18]), but due to conflict between her siblings regarding where she should live a guardian is required ([26])).

Further research undertaken by members of this group have shown that healthcare professionals involved in the care of persons with dementia tend to take a mediative approach to ‘consensus building’ in the context of family conflict over treatment decisions.¹⁷ We believe that this approach is potentially a very useful way of pre-empting the need for tribunal decision-making, providing that the rights, will and preference of the person with dementia are kept central to the process of consensus building. This approach could be safeguarded by providing access to an independent body, who can provide mediation services in the context of cases that might otherwise go to the full tribunal. Such a process is already in operation in South Australia, and is mandatory for any matters relating to Guardianship or Administration, prior to the matter being heard by the South Australian Civil and Administrative Tribunal (SACAT). This process is also optional for disputes relating to Advance Care Directives or health care decisions, without the matter necessarily having to go to the SACAT.¹⁸

RECOMMENDATION FIVE: That the legislation be amended to introduce a formal process of mediation in circumstances of familial conflict and that this be a mandatory precondition for tribunal consideration of a guardianship (and/or administration) order. The process of mediation should include participation of relevant professionals (e.g. health care professionals or social workers).

The most obvious way forward in this area would be to give such mediation powers to the NSW Public Trustee and Guardian. We envisage this could be done as it has been done in South Australia, where the Public Advocate has powers to mediate disputes under the Advance Care Directives Act 2013 (SA), Part 7 Div 2 and the Consent to Medical Treatment and Palliative Care Act 1995 (SA), Part 3A, Div 2.

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¹⁷ Blake M, Sinclair C, Doray O, ‘Does personal autonomy matter? Advance care planning for those with dementia in Western Australia: An examination of the fit between the law and practice’ (in preparation)

¹⁸ South Australian Civil and Administrative Tribunal Act (2013) s. 51.

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Thank you for the opportunity to provide this submission.

Disclaimer: The contents of the above materials are solely the responsibility of the individual authors identified, and do not reflect the views of the NHMRC or any other Funding Bodies or the Funding Partners.