

Cognitive Decline Partnership Centre Activity 24 Project Team

Submission to the NSW Law Reform Commission Inquiry into the Guardianship Act 1987 (NSW) – Question Paper 5

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 consumer experience in dementia care, and professional 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. In particular, this submission draws from preliminary evidence collected from:

- examination of legislation and case law relating to Guardianship and supported decision-making across three jurisdictions in Australia, and one overseas (WA, NSW, SA, and British Columbia), with particular reference to people with dementia;
- interviews with people living with dementia and their family carers, investigating their experiences with decision-making;
- interviews with aged-care service providers, investigating their established policies and practices with respect to healthcare and lifestyle decision-making among recipients of aged-care services.

Terms of Reference:

Considering the scope of this research project, and the fact that our work is still underway, 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.

Question 2.1: “Incapable of giving consent”

2.1(1) Is the definition of a person “incapable of giving consent to the carrying out of medical and dental treatment” in s 33(2) of the *Guardianship Act 1987 (NSW)* appropriate? If not, what should the definition be?

We do not consider the definition to be appropriate, for the following reasons:

- The definition is worded in the negative
- The definitions at the beginning of the Act (which appear to relate to ‘capacity’)¹ do not match this statement in s 33(2)
- There is no clear definition of “capacity”, which could be used to clarify the notion of a person who is capable or incapable of giving consent to medical or dental treatment, in the Act;
- Using the definition in the Queensland legislation² (based on *Gibbons v Wright*) would ensure consistency throughout the *Guardianship Act 1987* (NSW). By this we mean:

capacity, for a person for a matter, means the person is capable of –
 (a) understanding the nature and effect of decisions about the matter; and
 (b) freely and voluntarily making decisions about the matter; and
 (c) communicating the decisions in some way

2.1(2) Should the definition used to determine if someone is capable of consenting to medical or dental treatment align with the definitions of capacity and incapacity found elsewhere in the *Guardianship Act 1987* (NSW)? If so, how could we achieve this?

Yes, as per the above response 2.1(1), by a clear definition of ‘capacity’, which is then taken to apply to whether a person is capable of consenting to medical or dental treatment.

Question 3.3: Treatment by a registered health practitioner

Should the definition of medical and dental treatment in Part 5 of the *Guardianship Act 1987* (NSW) include treatment by a registered health practitioner?

Yes, but only if the treatment required by the person lacking the capacity to give consent is within the legislative scope and experience of the health practitioner.

Question 3.4: Types of treatment covered by Part 5

3.4(1) Are there any other types of treatment excluded from Part 5 of the *Guardianship Act 1987* (NSW) (or whose inclusion is uncertain) that should be included?

The difficulty when listing all types of treatment, is that there may be occasions when a different and/or new treatment is proposed and is not specifically listed. This would then require constant amendments to the legislation. It may be more appropriate therefore that an underlying principle should be applied as to the effect of various treatments, such as set out in the *Guardianship Regulation 2016* (NSW).³

Question 4.1: Special treatment

4.1(3) How should a patient’s objection be taken into account?

¹ Guardianship Act 1987 (NSW) s 3(2).

² Guardianship and Administration Act 2000 (QLD) Schedule 4

³ Guardianship Regulation 2016 (NSW) s10(1)(f)

The first consideration should be whether, with appropriate support, they are in a position to understand their situation and the proposed treatment, and whether this would enable them to refuse consent. If this is not possible, then a patient's objection could be taken into account by requiring the person authorising the treatment to consider:

- The person's current views
- What, if any, views they had expressed in the past

In the case of a person deemed to be incapable of giving consent (even with support), their past and current views could be considered as part of a process of identifying any alternatives to the proposed treatment, which might achieve the same ends, and be more in line with the person's preferences.

Question 4.5: Categories of treatment as a whole

4.5(1) Does the legislation make clear what consent requirements apply in any particular circumstance? If not, how could it be clearer?

Yes, for those areas that fall under Special, Major and Minor

4.5(2) Do you have any other comments about the treatment categories and associated consent regime in Part 5?

No

Question 4.6: Person responsible

4.6(1) Is the "person responsible" hierarchy appropriate and clear? If not, what changes should be made?

The current hierarchy appears to address all categories of persons, however, in practice conflict/confusion can arise in ss(d) where all parties have equal standing. Some guidance should be provided so that those persons included in this category have a clearer understanding of their role and third parties know who they can rely upon to provide consent for the person with cognitive impairment. Furthermore, provision should be made in the legislation as to when the 'person responsible' can give consent on behalf of a person with impaired decision-making capacity i.e. instead of whenever the person is "totally or partially" incapable. Neither "totally or partially" is defined. This goes back to the initial problem, that is, that there is no definition of "capacity" in the legislation.

4.6(2) Does the hierarchy operate effectively? If not, how could its operation be improved?

See response supra 4.6 (1). Also, those persons appointed as either an enduring guardian, or a guardian will have, within their document of appointment instructions on what they can/cannot consent to, this is not clearly defined for those in ss(b), (c) and (d) of s33A of the Act.

Question 4.9: Supported decision-making for medical and dental treatment decisions

4.9(1) Should NSW have a formal supported decision-making scheme for medical and dental treatment decisions?

Yes, this would remove any uncertainty in respect of what is meant by supported, as opposed to substitute decision-making.

4.9(2) If so, what should the features of such a scheme be?

The legislation should clearly define what is meant by supported decision-making, define “mental capacity” and the situations (including guidance) in which the supporter can assist the individual. The more detailed features of such a scheme would be consistent with what we have previously submitted (item 5.1(2) Question Paper 2):

- Formal supported decision-making agreements would be optional agreements. Entry into such an agreement might be encouraged by service providers, family members or the person in need of decision-making support, but are not compulsory;
- The supporter (or supporters) would be chosen by the person who is in need of decision-making support;
- The person may revoke the supported decision-making agreement if they choose, and may establish a supported decision-making agreement with another person (or persons);
- The person nominated as the supporter could choose to accept or decline the nomination, and this would be established prior to the supported decision-making agreement taking effect;⁴
- Provision should be made for people to establish formal supported decision-making agreements in advance, to be enacted at a time of their choosing, or in situations where they would otherwise be deemed to be incapable of making the decision on their own, without support.

4.10: Consent for sterilisation

4.10(1) Who, if anyone, should have the power to consent to sterilise a person?

The Guardianship Division of NCAT, taking into consideration the views of the individual and the “person responsible” and the reasons for the sterilisation.

4.10(2) In what ways, if any, could the *Guardianship Act 1987 (NSW)* better uphold the right of people with decision-making capacity to participate in a decision about sterilisation?

In the first instance there needs to be a definition of “mental capacity” to determine whether the person actually lacks the decision-making capacity in respect of the decision at hand. It may be that with appropriate support, the person is able to participate in this decision. Beyond this, see above 4.10(1) about the authorising body taking into account the views of the individual and their “person responsible”.

4.13: Legislative recognition of advance care directives

4.13(1) Should legislation explicitly recognise advance care directives?

⁴ This agreement would include their acknowledgment of the ‘duties and responsibilities’ associated with the role, which could also be specified in the legislation as per our submission to Question 5.1 in Question Paper 4.

Yes, but for the purpose of certainty for medical and allied health professionals. Whilst NSW relies on common law e.g. *Hunter and New England Area Health Service v A* and *Re JS* it is not uncommon to hear from the medical profession (and allied health workers) that advance care directives are not binding in NSW because there is no legislation. On the other hand all the evidence we have from Australia suggests that advance directives remain problematic in jurisdictions with legislation.

We suggest that any consideration with respect to legislating in this area should take into account the experience in other jurisdictions, and consider the additional value of moving toward national consistency, to enable the recognition of advance care directives created in other jurisdictions. On this point, we also consider that it is important that legislation and the publication of a prescribed form should not negate the existing common law provisions, or existing 'non-statutory' advance care directives. The WA legislation provides a useful model in this regard,⁵ as does the UK's *Mental Capacity Act 2005*, which creates minimum standards but does not require any particular form.

People completing an advance care directive should be encouraged to seek medical and/or legal advice – this process of recommending that advice be sought can be built into the witnessing of the document by the 'authorised' witness.

4.13(2) If so, is the *Guardianship Act 1987* (NSW) the appropriate place to recognise advance care directives?

Yes.

Question 4.14: Who can make an advance care directive

Who should be able to make an advance care directive?

Anyone over the age of 18 and possessing the requisite mental capacity (which should be defined in the legislation as per our answer to 2.1). This should also include those who could make an advance care directive with support.

Question 4.15: Form of an advance care directive

What form should an advance care directive take?

A model form should be published through NSW Health, which is simple and concise. However this should not be prescribed as the experience from Victoria shows that it is important for different health communities to be able to create their own directives.

Question 4.16: Matters an advance care directive can cover

What matters should an advance care directive be able to cover?

An advance care directive should, at a minimum, be able to cover all areas of treatment, and the refusal of any treatments that a person (when deemed capable to give or refuse consent) could refuse. We see value in taking this opportunity of documenting treatment preferences to also discuss preferences

⁵ Guardianship and Administration Act 1990 (WA) s 110ZB

for future living arrangements, and the broader values a person might have with respect to treatment decision-making, in cases where an ACD may not be able to specify all possible scenarios. However, domains such as living arrangements are difficult to prescribe in advance, or to uphold as 'legally binding'. People already have the option within the existing Enduring Guardianship form, to make statements about their values and preferences with respect to issues such as living arrangements. Such guidance could be included in accompanying documentation. Advance directives should also include consent to organ donation and ante-mortem interventions.

Question 4.17: When an advance care directive should be invalid

In what circumstances should an advance care directive be invalid?

In circumstances where it can be proved that the person making the advance care directive either lacked the requisite mental capacity, was a minor, or was subject to undue influence or unconscionable conduct. Specific treatment decisions might be overridden if situations had changed since the time of making the document (for example the discovery of a cure), which would have led the person to make a different decision. The interpretation of such situations will no doubt be made more practical by providing space and encouragement for people to articulate their goals and values for treatment, at the time of making their advance care directive.

Project Team:

The full list of investigators on the project is provided below:

Dr Craig Sinclair (University of Western Australia)
Prof. Meera Agar (University of Technology Sydney)
Sue Field (Western Sydney University)
Prof. Susan Kurrle (University of Sydney)
Kathy Williams (Alzheimer's Australia Consumer Representative)
Assoc. Prof. Meredith Blake (University of Western Australia)
Pia Castelli (University of Western Australia)
Prof. Cameron Stewart (University of Sydney)
Dr Sascha Callaghan (University of Sydney)
Prof. Romola Bucks (University of Western Australia)
Assoc. Prof. Josephine Clayton (University of Sydney)
Assoc. Prof. Kirsten Auret (University of Western Australia)
Karla Seaman (Brightwater Care Group)
Pippa Cebis (Brightwater Care Group)
Angelita Martini (Brightwater Care Group)
Kate Gersbach (Brightwater Care Group)
Meredith Gresham (HammondCare)
Rebecca Forbes (HammondCare)
Julie Bajic (HammondCare)
Helen Radoslovich (Helping Hand Aged Care)
Michelle Hogan (Helping Hand Aged Care)

Of this team, the following contributors were available to review and approve this document prior to submission:

Sue Field, Cameron Stewart, Craig Sinclair, Romola Bucks

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.