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Dear Commissioner

Submission to the *Review of the Guardianship Act 1987 (NSW)* Question Paper 5: Medical and dental treatment and restrictive practices

Executive summary

We recommend that:

1. The current definitions of capacity in the *Guardianship Act 1987 (NSW)* ('the Act') be replaced by a new, single definition of capacity, applicable to all aspects of guardianship, including advance care planning and end-of-life decision-making. The legislation should also include a statement that certain factors or characteristics do not, of themselves, demonstrate a lack of capacity.
2. If a separate statutory framework for Advance Care Directives (ACDs) is created in New South Wales, the definition of capacity in that legislation be consistent with whichever definition is ultimately adopted in the Act.
3. Part 5 of the Act specify who can consent to withholding and withdrawing life-sustaining treatment for a person with impaired decision-making capacity, including the power to refuse life-sustaining treatment.
4. The distinction between 'health care' decisions and 'medical and dental treatment' decisions be removed so that all substitute decision-makers have power to withhold or withdraw life-sustaining treatment.
5. In relation to the person responsible hierarchy:
 - Where there is more than one potential decision-maker on the 'same level', for example two guardians, a process for dispute resolution be introduced.
 - A person responsible not be required to put in writing their desire not to be a decision-maker.
 - The Public Guardian be added as the final person in the hierarchy.
6. Legislation explicitly recognising ACDs be introduced to make ascertaining the law easier, achieve greater certainty, improve the clarity of the law, and promote autonomy. Careful consideration should be given to existing legislative models, the restrictions that they

impose, and the effect of those restrictions on the ability of individuals to make an advance refusal of life-sustaining treatment.

Background

We are the Directors and Coordinator of the Australian Centre for Health Law Research (ACHLR), a specialist research Centre within the Queensland University of Technology's Faculty of Law. The Centre undertakes empirical, theoretical and doctrinal research into complex problems and emerging challenges in the field of health law, ethics, technology, governance and public policy.

End of life is one of the Centre's three research programs. Within that program, our Centre's academics undertake research which explores legal, ethical and policy issues in death, dying and decision-making, including: withholding and withdrawing life-sustaining medical treatment; provision of futile treatment at the end of life; advance care planning; palliative care; euthanasia and assisted suicide; and coronial systems and regulation.

Our research has examined issues relating to death, dying and decision-making at the end of life in all Australian jurisdictions, including New South Wales (NSW). Our research has identified significant issues for reform relating to the law at end of life in NSW, particularly in the areas of capacity, advance directives, withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity, and powers of substitute decision-makers.

These issues are discussed comprehensively in the article Ben White, Lindy Willmott, Pip Trowse, Malcolm Parker and Colleen Cartwright, 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales)' (2011) 18(3) *Journal of Law and Medicine* 498-522 (which we attach for the Commission's consideration), however we address many of the key issues identified in that article in this submission.

This submission builds upon our preliminary submission to this Review dated 4 April 2016. Due to time constraints we are unable to respond to each question in Question Paper 5. Accordingly, we address select issues only, based on some key areas for reform which we have identified in our research.

Please note this submission represents the personal views of the authors, and does not necessarily represent the views of other members of ACHLR or any other organisation with which any of the authors are affiliated. For this reason, we request that any mention of this submission refers to the named authors and not ACHLR as an entity.

Response to Question Paper 5

Capacity to consent to medical and dental treatment

Question 2.1: "Incapable of giving consent"

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

(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?

The determination of capacity is a threshold issue for medical treatment at the end of life, perhaps most significantly when the issue of withholding or withdrawing life-sustaining treatment arises. The NSW law contains three possible definitions for determining whether an adult has capacity. The first is the common law definition of capacity (applied for advance directives) described in *Hunter and New England Area Health Service v A* (2009).¹ The other two definitions are contained in the *Guardianship Act 1987* (NSW) ('the Act'): in section 14(1), which is relevant in determining whether a person is 'in need of a guardian' and in section 33(2), when determining whether a person is 'incapable of giving consent' for medical and dental treatment.

The existence of multiple definitions is undesirable, confusing and creates unnecessary complexity. It is suggested that a single definition for capacity be adopted in the Act. It should apply to all assessments of capacity and not just in relation to medical and dental treatment.

One option is to utilise one of the current definitions in the Act. If this approach is adopted, we favour the definition 'incapable of giving consent', which gives effect to the functional approach to capacity. This reflects the least restrictive approach favoured by modern guardianship law by recognising that a person may have capacity for some matters but not others, and is less uncertain and restrictive² than the term 'in need of a guardian', which will only apply where a person has a 'disability' and meets particular criteria under the Act.³

However, our preferred view approach is to replace the existing definitions with a new, clearer definition of capacity, applicable to all aspects of guardianship, including advance care planning and end-of-life decision-making. We note the definition recommended by the New South Wales Parliament Legislative Council Standing Committee on Social Issues in its 2010 report on *Substitute decision-making for people lacking capacity*. In that report, the Committee noted the issues relating to the current definitions of capacity, and suggested:

"the legislative definition in NSW should define 'capacity' with reference to the ability to understand, retain, utilise and communicate information relating to the particular decision that has to be made, at the particular time the decision is required to be made, to foresee the consequences of making or not making the decision and to separate the concepts of 'incapacity' and 'disability'".

The Committee further recommended:

"That the legislative definition acknowledge the fact that a person's decision-making capacity varies from domain to domain and from time to time and defines 'capacity' in relation to a particular decision with reference to, but without being limited to, the following:

- *the ability to understand information relevant to the decision*
- *the ability to retain that information for a period that allows the decision to be made within an appropriate timeframe*
- *the ability to utilise that information in the decision-making process*
- *the ability to foresee the consequences of making or not making the decision*

¹ *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 at [25].

² New South Wales Parliament Legislative Council Standing Committee on Social Issues, *Substitute decision-making for people lacking capacity* (2010) [4.8] – [4.20].

³ *Guardianship Act 1987* (NSW) s3(2), s6A(1)(a).

- *the ability to communicate the decision to others.*

*That legislation should in addition ensure that a person is not considered incapable of making a particular decision simply on the basis of their having a disability”.*⁴

In supporting a new definition of capacity that is applicable across the Act and not limited to medical and dental treatment, we endorse an approach that clarifies the meaning of capacity as recommended above by the Parliamentary Committee. Assessments of capacity are critical and sometimes complex so a clear statement which explains how the legal test should be applied is important. We also note that some jurisdictions specify in their legislation that certain factors or characteristics do not, of themselves, demonstrate a lack of capacity.⁵ The Parliamentary Committee noted disability above as an example, but there other factors or characteristics such as making unwise decisions, or particular political or religious beliefs. While some of these factors may be relevant considerations, they should not be taken to mean a person lacks capacity. We consider there is merit in including such factors in the Act, to make clear that the focus should be on the person’s capacity to make a particular decision.

Capacity and Advance Care Directives

A related issue is the definition of capacity which should be adopted for statutory Advance Care Directives (ACDs). If a separate statutory framework for ACDs is created in NSW, to ensure clarity and avoid confusion the definition of capacity in that legislation should be consistent with whichever definition is ultimately adopted in the *Guardianship Act 1987* (NSW).

Types of medical and dental treatment

Question 3.1: Withholding or stopping life-sustaining treatment

- (1) Should Part 5 of the *Guardianship Act 1987* (NSW) state who, if anyone, can consent to withholding or stopping life-sustaining treatment for someone without decision-making capacity?**

We recommend Part 5 of the Act specify who can consent to withholding and withdrawing life-sustaining treatment for a person with impaired decision-making capacity (and for clarity, we confirm here that we mean power to refuse life-sustaining treatment – that is, to determine that a person does not get treatment). Currently, the issue of whether or not a substitute decision-maker can consent to or refuse life-sustaining treatment depends on the type of decision-maker, and the nature and scope of their appointment i.e. whether they are empowered to make decisions in relation to one, or both categories of medical decisions: ‘health care’ decisions and/or ‘medical and dental treatment’ decisions.

Following the decision of *FI v Public Guardian* [2008]⁶ the power to refuse life-sustaining treatment can be exercised only by some substitute decision-makers empowered with health care functions (such as a guardian or enduring guardian, depending on the scope of their appointment), and not by those whose power extends only to consenting to (or withholding consent to – but not refusing)

⁴ New South Wales Parliament Legislative Council Standing Committee on Social Issues, n2, 35.

⁵ See for example *Advance Care Directives Act 2013* (SA) s7(2); *Advance Personal Planning Act* (NT) s6(5); *Mental Capacity Act 2005* (UK) s1(3) and (4).

⁶ *FI v Public Guardian* [2008] NSWADT 263.

medical and dental treatment (such as a person responsible, or a guardian who is granted more limited power).

This has resulted in an undesirable gap in the law, which may necessitate an application to the NSW Civil and Administrative Tribunal (NSWCAT) to determine the matter, or for the appointment of a guardian with requisite powers. These distinctions also create problems and further confusion for medical professionals as in practice they will need to know that these differences exist and to distinguish between decision-makers and the scope of their powers. Our research has demonstrated that significant knowledge deficits about the law at end of life, including confusion about what the law is and how it should be applied is, are common amongst medical practitioners most frequently practising in the end-of-life field, creating risks for both doctors and patients.⁷ Accordingly, to limit confusion and error, it is desirable for the legislation to clarify who may make a decision that life-sustaining treatment be withheld or withdrawn.

(2) Who should be able to consent and in what circumstances?

Currently in NSW, whether or not a substitute decision-maker can consent to or refuse life-sustaining treatment depends on the type of decision-maker, and the appointment made:

- An **Enduring Guardian** may have the power, under an Enduring Guardianship document, to consent to one or both of the following:
 - **Health care.** This includes the power to *refuse* life-sustaining treatment.
 - **Medical or dental treatment decisions.** In this situation the Enduring Guardian cannot refuse treatment and require that life-sustaining treatment be withheld or withdrawn. They can, however, decide not to consent to that treatment which could lead to it not being provided.
- The power of a **guardian** (including the NSW Public Guardian if appointed guardian) to consent to health care will depend on whether the NCAT makes a plenary or 'full' appointment:
 - If there is a **plenary appointment**, the guardian can make all the decisions that the person could have made if they had capacity, including power to consent to or refuse health care (including life-sustaining treatment).
 - If there is a **limited appointment** and the NCAT has granted that guardian power to make decisions about health care, then that will include the power to consent to or refuse life-sustaining treatment. However, if the 'limited' guardian is only able to consent to medical or dental treatment, they will not be able to refuse life-sustaining treatment. Despite this, the guardian could choose to withhold his or her consent to treatment, which may result in life-sustaining treatment not being given, and would have a similar effect as refusing treatment.
- A **person responsible** may consent to medical treatment, but does not have the power to refuse or withdraw consent to treatment, including life-sustaining treatment. A person responsible can however withhold consent to that treatment, which may result in life-sustaining treatment not being given (and may have a similar effect as refusing treatment).

⁷ Ben White, Lindy Willmott, Colleen Cartwright, Malcolm Parker and Gail Williams, 'Doctors' knowledge of the law on withholding and withdrawing life-sustaining medical treatment' (2014) 201(4) *Medical Journal of Australia* 229-232.

The above discussion demonstrates that the law is confusing, complex, and has led to the uncertainty described above. We suggest that the distinction between power to make decisions about health care and about medical treatment be removed. In practice, there may also be limited difference between the powers as a decision to withhold consent to treatment may mean that it is not provided (and as such, leads to the same result as a refusal of treatment).

We also recommend that *all* substitute decision-makers have the proposed unified power to make decisions about health care (which would include power to make decisions to withhold or withdraw life-sustaining treatment). This would include the person responsible as the default decision-maker. We note arguments that a person responsible has not been appointed and so should not have this power. However, in Queensland, South Australia and Western Australia, for example, default decision-makers automatically have this power and we are unaware of these concerns being problematic under those regimes. It is also pertinent to note that there are a number of safeguards that protect adults from inappropriate decision-making. One significant safeguard is the gatekeeping role played by medical professionals. A medical professional has a range of avenues to challenge a decision if he or she is concerned about it.

Accordingly, we favour removing the distinction between the health care function and the consent to medical and dental treatment function so that all substitute decision-makers have power to withhold or withdraw life-sustaining treatment.

Question 4.6: Person responsible

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

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

We make three comments in relation to the person responsible hierarchy. The first relates to where there may be more than one potential decision-maker on the ‘same level’, for example, two guardians. Question Paper 5 notes the options of either specifying how one of these decision-makers be given priority, or that the legislation establish a process for dispute resolution. We favour the latter approach. It would be very difficult to identify a rational basis to distinguish what would be appropriate in all circumstances in advance, so we consider this option is impractical or at best overly complex. We prefer establishing a process for resolving disputes (and note that these sorts of disputes arise relatively infrequently).

The second comment relates to the requirement for a person responsible to put in writing their desire not to be a decision-maker. At times of trauma, this can be unnecessarily stressful and unhelpful. We agree that it should not be required and note that where there are issues of who is an appropriate decision-maker, doctors should be recording in the patient’s health record the basis for accepting the authority of a particular person and not another who may be ahead in the hierarchy. As such, there would be a written record to evidence the desire of a person not to decide.

Finally, we suggest the addition of the Public Guardian as the final person in person responsible hierarchy. This ensures that there is always a person responsible who can provide consent and it can avoid the need to appoint a guardian, thereby promoting a least restrictive approach.

Question 4.13: Legislative recognition of advance care directives

(1) Should legislation explicitly recognise advance care directives?

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

We consider that legislation explicitly recognising ACDs should be introduced. NSW is one of only two jurisdictions in Australia that does not prescribe a statutory regime for an adult making an advance directive, instead relying on the common law relating to advance directives. This approach is undesirable, particularly for medical professionals, many of whom are unaware of the common law and its requirements.⁸

Further, although the decision in *Hunter and New England Area Health Service v A* (2009) has made clear that advance directives will be recognised in Australia at common law, it is unclear how such recognition currently fits with the provisions of the *Guardianship Act 1987* (NSW). McDougall J in *Hunter* observed in relation to Part 5 of the Act that “to some extent and for some purposes, the Guardianship Act may give recognition to advance care directives”.⁹ It is not clear what His Honour meant by this comment.

A statutory advance directive framework for NSW would make ascertaining the law easier, achieve greater certainty, and improve the clarity of the law, which would assist medical professionals and the broader community to know and understand the law. The enactment of appropriately drafted legislation would also have the desirable effect of enhancing the role and recognition of advance directives as an expression of autonomy.

In terms of the specific legislative framework that should be adopted, we refer to previous work which outlines some of the key considerations that should guide reform. In particular, we note the following articles, and some points raised in each:

- Lindy Willmott, ‘Advance Directives and the promotion of autonomy: A comparative Australian statutory analysis’ (2010) 17(4) *Journal of Law and Medicine* 556-581.

This article notes the importance of the principle of autonomy in shaping the law on advance directives, and argues that statutory regimes have, for the most part, eroded rather than promoted autonomy, particularly in the case of advance directives which refuse life-sustaining treatment. Given that the common law was shaped by the principle of autonomy, and it has been expressly noted that this principle overrides that of sanctity of life in the context of refusal of life-sustaining treatment, it should follow that the legislation also safeguards and promotes the autonomy of competent individuals to refuse such treatment.

Accordingly, if statutory advance directives are introduced in New South Wales, we consider these reforms should promote autonomy, and that careful consideration should be given to existing legislative models, the restrictions that they impose, and the effect of those restrictions on the ability of individuals to make an advance refusal of life-sustaining treatment. The Western Australian model provides a good example of legislation which does not impose restrictions about when an individual can complete a directive, when it will

⁸ Ibid.

⁹ *Hunter and New England Area Health Service v A* (2009) 75 NSWLR 88 at [39].

operate, or provisions, over and above those that exist at common law, that excuse a medical professional for not following the directive.¹⁰

- Lindy Willmott, 'Advance directives to withhold life-sustaining medical treatment: eroding autonomy through statutory reform' (2007) 10(2) *Flinders Journal of Law Reform* 287-314.

This article focuses on the Queensland legislation that regulates an advance directive to withhold or withdraw life-sustaining medical treatment, which imposes more restrictions on an individual's ability to complete a binding and operative advance directive than any other Australian jurisdiction. It suggests that its restrictions on the operation of an advance directive unjustifiably infringe a competent adult's right to determine medical treatment.

It also compares the legal frameworks both at common law and under the legislation of the Australian States and Territories.

Conclusions reached in this article about the appropriate balance between autonomy and sanctity of life, in the context of the Queensland legislation, are equally relevant to the current review of the NSW Act.

Additionally, we make the following brief observations that an advance directive should:

- Enable an adult to both refuse future treatment and accept future treatment.
- Enable an adult to make specific decisions about particular treatment, or treatment in general, as well as provide values or guidance about goals of care.
- Enable an adult to refuse life-sustaining treatment. Where a directive does this, it should not be subject to additional constraints or limitations. These exist in Queensland under s103 of the *Powers of Attorney Act 1998* (Qld), but they have been criticised by the Queensland Law Reform Commission, which has recommended their removal.¹¹
- Be subject to some (limited) grounds whereby the directive need not be followed (for example, a change in the adult's circumstances). However, good medical practice should never be a basis for not following an advance care directive (as having different views about what treatment is wanted or not wanted at the end of life is often the reason why an adult has completed such a document). This excuse currently exists in Queensland but as noted has been criticised and reform recommended to remove it.

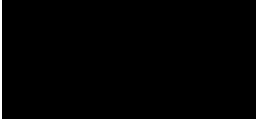
Our response to the questions in section 7 of Question Paper 5 (Restrictive Practices) will be addressed in a separate submission, led by a colleague who is an expert in that field.

¹⁰ The Western Australian model also encourages an individual to obtain information before completing a directive, but the advance directive is not invalid if the person chooses not to obtain such information: Lindy Willmott, 'Advance Directives and the promotion of autonomy: A comparative Australian statutory analysis' (2010) 17(4) *Journal of Law and Medicine* 556-581.

¹¹ Queensland Law Reform Commission, *A review of Queensland's Guardianship Laws* (2010), Report No. 67, vol 2 [9.276-9.343], 73-89 <http://www qlrc.qld.gov.au/___data/assets/pdf_file/0004/372541/r67_vol_2.pdf>.

Thank you for the opportunity to contribute to this review. We would be pleased to assist the Commission further if additional information is required.

Yours sincerely



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