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Law Reform Commission

Review of the Guardianship Act 1987

Question Paper 5

Medical and dental treatment and restrictive practices

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For more information about us, and our processes, see our website: www.lawreform.justice.nsw.gov.au.

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Terms of reference

Pursuant to section 10 of the *Law Reform Commission Act 1967*, the NSW Law Reform Commission is asked to review and report on the desirability of changes to the *Guardianship Act 1987* (NSW) having regard to:

1. The relationship between the *Guardianship Act 1987* (NSW) and
    - The *NSW Trustee and Guardian Act 2009* (NSW)
    - The *Powers of Attorney Act 2003* (NSW)
    - The *Mental Health Act 2007* (NSW)
    - other relevant legislation.
2. Recent relevant developments in law, policy and practice by the Commonwealth, in other States and Territories of Australia and overseas.
3. The report of the 2014 ALRC Equality, Capacity and Disability in Commonwealth Laws.
4. The UN Convention on the Rights of Persons with Disabilities.
5. The demographics of NSW and in particular the increase in the ageing population.

In particular, the Commission is to consider:

1. The model or models of decision making that should be employed for persons who cannot make decisions for themselves.
2. The basis and parameters for decisions made pursuant to a substitute decision making model, if such a model is retained.
3. The basis and parameters for decisions made under a supported decision making model, if adopted, and the relationship and boundaries between this and a substituted decision making model including the costs of implementation.
4. The appropriate relationship between guardianship law in NSW and legal and policy developments at the federal level, especially the *National Disability Insurance Scheme Act 2013*, the *Aged Care Act 1997* and related legislation.
5. 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.
6. Whether guardianship law in NSW should explicitly address the circumstances in which the use of restrictive practices will be lawful in relation to people with a decision making incapacity.
7. In the light of the requirement of the UNCRPD that there be regular reviews of any instrument that has the effect of removing or restricting autonomy, should the *Guardianship Act 1987* provide for the regular review of financial management orders.

8. The provisions of Division 4A of Part 5 of the *Guardianship Act 1987* relating to clinical trials.

9. Any other matters the NSW Law Reform Commission considers relevant to the Terms of Reference.

[Reference received 22 December 2015]

Recent Australian reviews of guardianship laws

In this Question Paper, we refer extensively to a number of recent Australian reviews:

- NSW, Legislative Council Standing Committee on Social Issues, *Substitute Decision-Making for People Lacking Capacity*, Report 43 (2010).
- Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws*, Report 67 (2010).
- Victorian Law Reform Commission, *Guardianship*, Final Report 24 (2012) – reflected in part in the Guardianship and Administration Bill 2014 (Vic) which the Victorian Parliament did not pass.
- Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report 124 (2014).
- Australian Capital Territory Law Reform Advisory Council, *Guardianship Report* (2016).
- Australian Law Reform Commission, *Elder Abuse*, Discussion Paper 83 (2016).

Questions

2. 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?

3. 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?

(2) If so, who should be able to consent and in what circumstances?

Question 3.2: Removing and using human tissue

(1) Should Part 5 of the *Guardianship Act 1987* (NSW) state who, if anyone, can consent to the removal and use of human tissue for a person who lacks decision-making capacity?

(2) If so, who should be able to consent and in what circumstances?

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?

Question 3.4: Types of treatment covered by Part 5

(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?

(2) Should any types of treatment included in Part 5 of the *Guardianship Act 1987* (NSW) be excluded?

4. Consent to medical and dental treatment

Question 4.1: Special treatment

(1) Is the definition of special treatment appropriate? Should anything be added? Should anything be taken out?

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

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

(4) In what circumstances could special treatment be carried out without consent?

Question 4.2: Major treatment

(1) Is the definition of major treatment appropriate? Should anything be added? Should anything be taken out?

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

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

(4) In what circumstances could major treatment be carried out without consent?

Question 4.3: Minor treatment

(1) Is the definition of minor treatment appropriate? Should anything be added? Should anything be taken out?

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

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

(4) In what circumstances could minor treatment be carried out without consent?

Question 4.4: Treatment that is not medical or dental treatment

Does the *Guardianship Act NSW* (1987) deal with treatments that fall outside of the Part 5 regime adequately and clearly?

Question 4.5: Categories of treatment as a whole

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

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

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?

Question 4.7: Factors that should be considered before consent

Are the factors a decision-maker must consider before consenting to treatment appropriate? If not, what could be added or removed?

Question 4.8: Requirement that consent be given in writing

Is the requirement that consent requests and consents must be in writing appropriate? If not, what arrangements should be in place?

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

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

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

Question 4.10: Consent for sterilisation

(1) Who, if anyone, should have the power to consent to a sterilisation procedure?

(2) In what ways, if any, could the *Guardianship Act 1987* (NSW) better uphold the right of people without decision-making capacity to participate in a decision about sterilisation?

Question 4.11: Preconditions for consent to sterilisation

What matters should the NSW Civil and Administrative Tribunal be satisfied of before making a decision about sterilisation?

Question 4.12: Matters that should not be taken into account in sterilisation decisions

(1) Is there anything the NSW Civil and Administrative Tribunal should *not* take into account when deciding about sterilisation?

(2) Should these be stated expressly in the *Guardianship Act 1987* (NSW)?

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?

Question 4.14: Who can make an advance care directive

Who should be able to make an advance care directive?

Question 4.15: Form of an advance care directive

What form should an advance care directive take?

Question 4.16: Matters an advance care directive can cover

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

Question 4.17: When an advance care directive should be invalid

In what circumstances should an advance care directive be invalid?

Question 4.18: Part 5 offences

(1) Are the various offences of treating without authorisation and the maximum penalties that apply appropriate and effective?

(2) Is there a need for any other offences relating to medical and dental treatment?

5. Clinical trials

Question 5.1: Definition of "clinical trial"

How should the *Guardianship Act 1987* (NSW) define "clinical trial"?

Question 5.2: Categories of medical research

(1) Should there be more than one category of medical research?

(2) If so, what should those categories be and what consent regimes should apply to each?

Question 5.3: Who can consent to clinical trial participation

(1) Who should be able to approve a clinical trial?

(2) Who should be able to consent to a patient's participation in a clinical trial if the patient lacks decision-making capacity?

(3) How can the law promote the patient's autonomy in the decision-making process?

Question 5.4: Considering the views and objections of patients

(1) If the patient cannot consent, should the decision-maker be required to consider the views of the patient?

(2) What should happen if a patient objects to participating in a clinical trial? Should substitute consent be able to override a patient's objection? If so, in what circumstances?

Question 5.5: Preconditions for consent

What preconditions should be met before a decision-maker can consent to participation?

Question 5.6: Requirements after consent

What should researchers be required to do after consent is obtained?

Question 5.7: Waiver of clinical trial consent requirements

Are there any circumstances in which the individual consent requirements for clinical trials should be waived?

Question 5.8: Other issues

Do you have any other comments about the consent requirements for clinical trials?

6. The relationship between the *Guardianship Act* and mental health legislation

Question 6.1: Relationship between the *Guardianship Act* and the *Mental Health Act*

(1) Is there a clear relationship between the *Guardianship Act 1987* (NSW) and the *Mental Health Act 2007* (NSW)?

(2) What areas, if any, are unclear or inconsistent?

(3) How could any lack of clarity or inconsistency be resolved?

Question 6.2: Relationship between the *Guardianship Act* and the *Forensic Provisions Act*

(1) Is there a clear relationship between the *Guardianship Act* and the *Forensic Provisions Act*?

(2) What areas, if any, are unclear or inconsistent?

(3) How could any lack of clarity or inconsistency be resolved?

Question 6.3: Whether mental health laws should always prevail

(1) Is it appropriate that mental health laws prevail over guardianship laws in every situation?

(2) If not, in which areas should this priority be changed?

7. Restrictive practices

Question 7.1: Problems with the regulation of restrictive practices

What are the problems with the regulation of restrictive practices in NSW and what problems are likely to arise in future regulation?

Question 7.2: Restrictive practices regulation in NSW

(1) Should NSW pass legislation that explicitly deals with the use of restrictive practices?

(2) If so, should that legislation sit within the *Guardianship Act* or somewhere else?

(3) What other forms of regulation or control could be used to deal with the use of restrictive practices?

Question 7.3: Who should be regulated?

Who should any NSW regulation of the use of restrictive practices apply to?

Question 7.4: Defining restrictive practices

How should restrictive practices be defined?

Question 7.5: When restrictive practices should be permitted

In what circumstances, if any, should restrictive practices be permitted?

Question 7.6: Consent and authorisation mechanisms

(1) Who should be able to consent to the use of restrictive practices?

(2) What factors should a decision-maker have to consider before authorising a restrictive practice?

(3) What should be the mechanism for authorising restrictive practices in urgent situations?

(4) What changes, if any, should be made to NSW's consent and authorisation mechanisms for the use of restrictive practices?

Question 7.7: Safeguards for the use of restrictive practices

What safeguards should be in place to ensure the appropriate use of restrictive practices in NSW?

Question 7.8: Requirements about the use of behaviour support plans

(1) Should the law include specific requirements about the use of behaviour support plans?

(2) If so, what should those requirements be?

1. Introduction

In brief

The *Guardianship Act 1987* (NSW) allows someone to make decisions about medical and dental treatment for a person with impaired decision-making capacity. We seek your views about this law. We also seek your views about whether we need specific laws to regulate the use of "restrictive practices".

Key concepts 2
Outline of Question Paper 5 3

1.1 The NSW Attorney General has asked us to review the *Guardianship Act 1987* (NSW) ("*Guardianship Act*"). This document (Question Paper 5) is one of a series of question papers in which we ask if aspects of the *Guardianship Act* need to change.

1.2 The law in NSW recognises that some people may be incapable of making decisions about important issues in their life. The *Guardianship Act* allows someone to be identified or appointed to make personal, financial, medical and dental decisions for a person with impaired decision-making capacity.

1.3 This paper looks at two distinct areas of guardianship law. The first area is the alternative decision-making arrangements that apply when someone is incapable of giving valid consent to their own medical or dental treatment. We consider:

- who should be able to consent to medical and dental treatment for someone else
- in what circumstances they should be able to consent, and
- whether the law sets out clearly enough what arrangements apply and when.

We also consider the related question of who can authorise a person to participate in medical research and in what circumstances.

1.4 This paper also looks at what are known as "restrictive practices". A restrictive practice is generally understood to be "any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability, with the primary purpose of protecting the person or others from harm".[1] There is no law in NSW that specifically regulates the use of restrictive practices. We consider:

- the current law regarding the use of restrictive practices
- the likely impact of the National Disability Insurance Scheme ("NDIS") Quality and Safeguarding Framework
- whether the *Guardianship Act* should regulate restrictive practices, and

1. Australia, Department of Social Services, *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* (2013) 4.

- if so:
  - how to define restrictive practices
  - in what situations, if any, restrictive practices should be lawful, and
  - who should be able to consent to and authorise their use.

Key concepts

1.5 Here are some of the key terms we use in this paper.

- **Advance care directive:** when a person speaks or writes their instructions or preferences for their medical care in anticipation of a time when they can no longer make their own medical decisions. An advance care directive is sometimes called an "advance care plan," an "advance health plan" or a "living will".
- **Alternative decision-making arrangement:** when someone makes or is involved in reaching a decision about another person's financial, medical or personal affairs. Such arrangements may include (but are not limited to) co-decision-making, substitute decision-making and supported decision-making.
- **Alternative decision-maker:** a person who makes or is involved in reaching a decision under an alternative decision-making arrangement.
- **Life-sustaining treatment:** a treatment that maintains vital bodily functions when a patient, for example, cannot breathe, eat or drink independently. These treatments are sometimes also called "life-sustaining measures".
- **Medical research:** research that involves investigating or evaluating health matters and medical interventions.
- **Palliative care:** treatment carried out to relieve a patient's pain and discomfort at the end of their life.
- **Patient:** a person who is receiving medical or dental treatment, or for whom medical or dental treatment is proposed.
- **Person responsible:** the person who is responsible for consenting to medical or dental treatment on a patient's behalf under Part 5 of the *Guardianship Act*. See section 33A.
- **Restrictive practice:** any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability, with the primary purpose of protecting that person or others from harm.
- **Sterilisation:** treatment that makes a person infertile.
- **Substitute decision-maker:** a person who makes decisions on behalf of and instead of another person.
- **Substitute decision-making:** when someone else makes decisions on behalf of and instead of someone who lacks decision-making capacity.

- **Supported decision-making:** when a person makes their own decision with the help of a supporter. For example, a supporter might collect information, explain what the person should take into account or help the person to communicate their decision.
- **Supporter:** someone who supports or helps another person to make their own decision.
- **Termination:** a medical treatment that ends a pregnancy. This is also known as an abortion.

Outline of Question Paper 5

1.6 This Question Paper deals with the following topics:

- **Chapter 2** looks at the definition of "incapable of giving consent" to medical or dental treatment.
- **Chapter 3** considers the types of treatment included in the consent regime established by Part 5 of the *Guardianship Act*.
- **Chapter 4** considers the consent requirements for medical and dental treatment, including who can consent to sterilisation and the effect of advance care directives.
- **Chapter 5** considers who can authorise a person to participate in a clinical trial and in what circumstances.
- **Chapter 6** looks at the relationship between the *Guardianship Act* and mental health legislation.
- **Chapter 7** considers the current law regarding the use of restrictive practices and the likely impact of the NDIS Quality and Safeguarding Framework. It also asks whether the *Guardianship Act* should explicitly address when the use of restrictive practices on people with impaired decision-making capacity is lawful.

2. Capacity to consent to medical and dental treatment

In brief

When a person is incapable of giving consent to their own medical or dental treatment, a substitute decision-maker may make treatment decisions for them. This Chapter considers what it means to be "incapable of giving consent".

2.1 Part 5 of the *Guardianship Act 1987* (NSW) ("*Guardianship Act*") allows someone to make decisions about a patient's medical and dental treatment if the patient is incapable of giving consent. In this Chapter, we seek your views on the definition of "incapable of giving consent".

2.2 A patient is considered incapable of giving consent if the patient:

(a) is incapable of understanding the general nature and effect of the proposed treatment, or

(b) is incapable of indicating whether or not he or she consents or does not consent to the treatment being carried out.[1]

2.3 The concepts of "capacity" and "incapacity" are key elements in guardianship law in NSW and elsewhere. Generally, a person must be incapable of making their own decisions before a substitute decision-maker can make decisions for them.

2.4 In Question Paper 1 we discussed the concept of capacity in detail, including how:

- the laws in other places define decision-making capacity
- new ideas about capacity have led to some fundamental changes to guardianship laws around the world (for example, some laws in other places recognise that impaired capacity may be partial, temporary or fluctuating)
- some laws in other places expressly provide what should *not* lead to a finding of incapacity
- the support and assistance available to someone may be relevant to assessing their capacity, and
- bringing in professional assistance may help in assessing a person's capacity.[2]

2.5 You may want to read Chapter 3 of Question Paper 1 to learn more about these developments before answering Question 2.1.

2.6 The *Guardianship Act* and other NSW laws define decision-making capacity in a variety of ways. For example, in the case of guardianship orders, the Tribunal must be satisfied that a person has a disability before it can find that they lack capacity to

1. *Guardianship Act 1987* (NSW) s 33(2).
2. NSW Law Reform Commission, *Preconditions for Alternative Decision-Making Arrangements*, Review of the Guardianship Act 1987 Question Paper 1 (2016).

make a decision. This is *not* required, for example, for financial management orders or decisions about medical and dental treatment.[3]

2.7 Stakeholders have told us that having different definitions of capacity and incapacity is confusing.[4] One idea is to introduce a single definition that applies in all the different circumstances covered by the *Guardianship Act*. On the other hand, there might be good reasons why the term "incapable of giving consent" needs its own definition in the context of 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?

3. *Guardianship Act 1987* (NSW) s 3 definition of "person in need of a guardian", s 14(1), s 25E(1), s 32(a), s 33(2), s 44(1).

4. See, eg, Australian Centre for Health Law Research, *Preliminary Submission PGA47*, 3.

3. Types of medical and dental treatment

In brief

When a person is incapable of making their own medical decisions, a substitute decision-maker may make those decisions for them. This Chapter considers what types of treatment a substitute decision-maker can consent to under Part 5 of the *Guardianship Act 1987* (NSW).

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3.1 Part 5 of the *Guardianship Act 1987* (NSW) ("*Guardianship Act*") sets out the alternative decision-making arrangements that apply when someone is incapable of consenting to their own medical or dental treatment. Depending on the type of treatment, a "person responsible"[1] or the Guardianship Division of the NSW Civil and Administrative Tribunal ("Tribunal") can consent to treatment. We discuss who can be a "person responsible" in Chapter 4.

3.2 This Chapter seeks your views on the types of treatment to which Part 5 applies.

Types of treatment covered by Part 5

3.3 Part 5 provides different consent arrangements depending on the type of treatment proposed. The types of treatment to which the Part 5 consent arrangements apply are:

> (a) medical treatment (including any medical or surgical procedure, operation or examination and any prophylactic, palliative or rehabilitative care) normally carried out by or under the supervision of a medical practitioner, [and]
>
> (b) dental treatment (including any dental procedure, operation or examination) normally carried out by or under the supervision of a dentist.[2]

3.4 In the case of treatment in the course of a clinical trial, the arrangements also apply to the giving of placebos to some participants of the trial.[3]

3.5 Types of treatment specifically excluded from the Part 5 regime are:

- non-intrusive examinations made for diagnostic purposes

1. Defined in *Guardianship Act 1987* (NSW) s 33A.
2. *Guardianship Act 1987* (NSW) s 33(1)(a)–(b) definition of "medical or dental treatment".
3. *Guardianship Act 1987* (NSW) s 33(1) definition of "medical or dental treatment".

- medical and dental first aid, and
- the administration of a drug that does not require a prescription – provided the drug is administered for the purpose, and in the dose, recommended by the manufacturer.[4]

3.6 These treatments have been excluded because they are of "such a minor nature or are so linked to day to day living and only carried out when necessary that it was inappropriate for consent to them to have to be sought through the substitute decision-making regime".[5]

Areas of uncertainty

Withholding or stopping life-sustaining treatment

3.7 When a person is dying and has no prospect of recovery a doctor might recommend stopping the treatment that is keeping them alive. However, it is not clear whether Part 5 authorises a person responsible to consent to withholding or stopping life-sustaining treatment.

3.8 A person responsible or the Tribunal can consent to "palliative care", but the Act does not define "palliative care".[6] It is therefore unclear whether this includes the act of withholding or stopping life-sustaining treatment.

3.9 The objects of Part 5 are:

> (a) to ensure that people are not deprived of necessary medical or dental treatment merely because they lack the capacity to consent to the carrying out of such treatment, and
>
> (b) to ensure that any medical or dental treatment that is carried out on such people is carried out for the purpose of promoting and *maintaining their health and well-being*.[7]

3.10 The person responsible and the Tribunal must consider these objects before deciding whether to consent to someone's treatment.[8] The requirement to consider whether treatment promotes and maintains a patient's "health and well-being" could be problematic when deciding whether to consent to stopping or withhold life-sustaining treatment.

3.11 In a 2006 case, the NSW Administrative Decisions Tribunal ("ADT"), reviewing a decision of the Public Guardian, held that Part 5 is not intended to cover the withdrawal of life-sustaining treatment.[9] The ADT also held that

> a power to consent to palliative care does not include a power to consent to withholding treatment which would, if administered, prolong life. If Parliament

4. *Guardianship Act 1987* (NSW) s 33(1)(d)–(f) definition of "medical or dental treatment".
5. N O'Neill and C Peisah, *Capacity and the Law* (Sydney University Press, 2011) [12.4.4.1].
6. *Guardianship Act 1987* (NSW) s 33(1) definition of "medical or dental treatment".
7. *Guardianship Act 1987* (NSW) s 32 (emphasis added).
8. *Guardianship Act 1987* (NSW) s 40(3)(c), s 44(2)(c).
9. *WK v Public Guardian (No 2)* [2006] NSWADT 121 [12]–[15].

> had intended to give the Guardianship Tribunal (and the Public Guardian) such a significant power, it would have done so expressly.[10]

3.12 However, the Guardianship Tribunal took another approach in 2007. It decided that the Public Guardian could make decisions to limit treatment as part of a palliative care plan. The Guardianship Tribunal said excluding the withdrawal of life-sustaining treatment from the definition of palliative care was "not in line with current clinical thinking".[11]

3.13 The Tribunal adopted yet another approach in 2008. It decided that Part 5 applied to decisions about "proactive medical interventions", rather than decisions to withdraw or withhold treatment. But it also said that a guardian could refuse life-sustaining treatment if they were authorised to do so by the terms of their appointment and it was in the person's best interests. The Tribunal further held that the medical practitioner did not need an alternative decision-maker's consent if the practitioner thought treatment would be futile.[12]

3.14 One stakeholder submits that the 2008 case creates confusion for medical professionals who must now distinguish between substitute decision-makers depending on the scope of their powers.[13] NSW Health submits that the case does not make clear whether persons responsible have the same powers as guardians to make decisions to stop or withhold treatment. As a result NSW Health currently advises clinicians that a guardian needs to be appointed to consent to the withholding or stopping of treatment. This process can take some time.[14]

3.15 The Supreme Court can consent to treatment for people who lack decision-making capacity under its inherent protective powers. For more on the Supreme Court's inherent powers see Question Paper 6, Chapter 11.[15] The Court must consider the proposed treatment is in the patient's best interests. In Australia, no court has explained when withholding or stopping life-sustaining treatment will be in a patient's best interests.[16] However, the supreme courts in NSW, Victoria and the Northern Territory have decided that it was not in a patient's best interests to receive life-sustaining treatment that is futile and/or excessively burdensome.[17]

3.16 The laws in some other states and territories make it clear that substitute decision-makers can consent to withdrawing or stopping life-sustaining treatment in some cases.

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10. *WK v Public Guardian (No 2)* [2006] NSWADT 121 [15].
11. *BAH* [2007] NSWGT 1 [50].
12. *FI v Public Guardian* [2008] NSWADT 263 [40], [51]–[53], [46].
13. Australian Centre for Health Law Research, *Preliminary Submission PGA47*, 3–4.
14. NSW Health, *Preliminary Submission PGA49*, 6.
15. NSW Law Reform Commission, *Remaining Issues*, Review of the Guardianship Act 1987 Question Paper 6 (2017).
16. L Willmott, B White and M K Smith, "'Best Interests' and Withholding and Withdrawing Life-Sustaining Treatment from an Adult who Lacks Capacity in the Parens Patriae Jurisdiction" (2014) 21 *Journal of Law and Medicine* 920, 920.
17. *Messiha v South East Health* [2004] NSWSC 1061 [22]–[23], [25]–[28]; *Application by Herrington: Re King* [2007] VSC 151 [24]–[25]; *Slaveski v Austin Health* [2010] VSC 493, 32 VR 129 [35], [51]–[52]; *Melo v Superintendent of Royal Darwin Hospital* [2007] NTSC 71, 21 NTLR 197 [27]–[30]. See also L Willmott, B White and M K Smith, "'Best Interests' and Withholding and Withdrawing Life-Sustaining Treatment from an Adult who Lacks Capacity in the Parens Patriae Jurisdiction" (2014) 21 *Journal of Law and Medicine* 920, 925–932.

3.17 In Queensland, guardians, attorneys or statutory health attorneys can make decisions about health care if a patient has not made a valid advance health directive that already deals with the issue.[18] "Health care" includes withholding or withdrawing a life-sustaining measure if starting or continuing the measure would be inconsistent with good medical practice.[19]

3.18 In the Australian Capital Territory ("ACT"), a person appointed under an enduring power of attorney can make decisions about "health care matters". The ACT uses a similar definition of "health care" to Queensland.[20]

3.19 In South Australia, a medical practitioner must withdraw life-sustaining measures if a patient's representative directs them to.[21] A patient's representative includes any person authorised to make decisions about relevant medical treatment for the patient.[22]

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?

(2) If so, who should be able to consent and in what circumstances?

Removing and using human tissue

3.20 The *Guardianship Act* does not say who can consent to removing and/or using the human tissue of a patient who lacks the capacity to consent. However, there is some guidance in the *Human Tissue Act 1983* (NSW). This Act says a person responsible may authorise the use of tissue that is removed from a patient during medical, dental or surgical treatment (as long as the patient is not deceased). Section 21Z provides tissue can be used for "therapeutic, medical or scientific" purposes.[23]

3.21 The Supreme Court considered the scope of section 21Z in 2005. The case was about an application to collect healthy stem cells and bone marrow from a patient who lacked the capacity to consent. The treatment was intended to benefit the patient's brother who had lymphoma. The Court said

> the proposed procedure is outside the class of medical treatment for which the person responsible may give consent under s 36(1)(a) of the [*Guardianship Act 1987* (NSW)]. That provision enables consent to medical treatment "on" a patient which, having regard to the usual principles of construction, I understand to mean medical treatment which directly affects that patient in that it is for the purpose of the promotion of his or her personal health.[24]

18. *Guardianship and Administration Act 2000* (Qld) s 66, s 66A.
19. *Guardianship and Administration Act 2000* (Qld) sch 2 cl 5(2).
20. *Powers of Attorney Act 2006* (ACT) s 12, s 13(2).
21. *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 17(2)(b).
22. *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 4(1) definition of "representative".
23. *Human Tissue Act 1983* (NSW) s 21Z.
24. *Northern Sydney and Central Coast Area Health Service v CT* [2005] NSWSC 551 [9].

3.22 Despite this, the Court authorised the tissue donation. The Court noted that although the patient was incapable of fully understanding the procedure, he had expressed a desire to participate and help his brother. In addition, the risks associated with the procedure were small and any side effects would be "mild and of short duration". Most significantly, the patient's brother, if he survived, would likely become the patient's principal carer.[25]

3.23 This approach can be contrasted with an earlier case in which a woman wanted to collect semen from her unconscious husband to use in IVF treatment after his death. The Court held that the Supreme Court's protective powers were to be exercised cautiously and not for the benefit of others. Since the procedure did not promote the well-being of the patient, the Court could not consent to it.[26]

3.24 In Tasmania and Victoria the relevant board or tribunal can authorise the removal of tissue for the purposes of transplantation.[27] The situation is similar in the ACT and Queensland. The law in these places requires the relevant board or tribunal to be satisfied of a range of factors, for example that the risk to the person from whom the tissue is being taken is small and other compatible donors are not available.[28] Queensland and the Northern Territory allow a person to consent in advance by including instructions in an advance health directive or plan.[29] Queensland specifies that consent cannot be given if the person objects.[30]

Question 3.2: Removing and using human tissue

(1) Should Part 5 of the *Guardianship Act 1987* (NSW) state who, if anyone, can consent to the removal and use of human tissue for a person who lacks decision-making capacity?

(2) If so, who should be able to consent and in what circumstances?

Treatment by someone other than a medical or dental practitioner

3.25 The *Guardianship Act* defines "medical and dental treatment" to include treatment "normally carried out by or under the supervision of" a medical practitioner or dentist. The former Minister for Health submits that it is unclear whether this includes health treatment provided by other registered health practitioners, for example, nurses and midwives, Aboriginal and Torres Strait Islander health practitioners, Chinese medicine practitioners, chiropractors, occupational therapists, optometrists, pharmacists, osteopaths, podiatrists, physical therapists and psychologists.[31]

25. *Northern Sydney and Central Coast Area Health Service v CT* [2005] NSWSC 551 [21], [27], [28].
26. *MAW v Western Sydney Area Health Service* [2000] NSWSC 358, 49 NSWLR 2310 [31], [41], [54].
27. *Guardianship and Administration Act 1995* (Tas) s 3(1) definition of "special treatment", s 39(1); *Guardianship and Administration Act 1986* (Vic) s 3(1) definition of "special procedure", s 39(1)(a).
28. *Guardianship and Management of Property Act 1991* (ACT) s 70(4); *Guardianship and Administration Act 2000* (Qld) s 69(1).
29. *Guardianship and Administration Act 2000* (Qld) s 65(2), s 66(2); *Guardianship of Adults Act* (NT) s 23.
30. *Guardianship and Administration Act 2000* (Qld) s 67.
31. NSW Minister for Health, *Preliminary Submission PGA55*, 1.

3.26 The absence of explicit reference to such treatments in the definition may raise doubts about whether these kinds of practitioners can lawfully treat a patient who lacks capacity. For example, in some emergency situations nurses and midwives have to give treatment without the supervision of a medical practitioner.

3.27 Expanding the definition of "medical and dental treatment" to include treatment provided by a registered health practitioner could ensure that patients who lack the capacity to consent are not prevented from receiving a wide range of health treatments.

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?

Question 3.4: Types of treatment covered by Part 5

(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?

(2) Should any types of treatment included in Part 5 of the *Guardianship Act 1987* (NSW) be excluded?

4. Consent to medical and dental treatment

In brief

Part 5 of the *Guardianship Act 1987* (NSW) has different rules for substitute consent depending on the type of medical or dental treatment. We seek your views on the different consent rules and whether NSW legislation should formally recognise medical supporters and advance care directives.

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4.1 Part 5 of the *Guardianship Act 1987* (NSW) ("*Guardianship Act*") sets out who can consent to medical or dental treatment for a person who is incapable of consenting. The Act sets out different consent requirements based on the following categories of treatment:

- special treatment
- major treatment, and
- minor treatment.

4.2 The consent requirements that apply in a particular case may also depend on factors such as:

- the urgency of the treatment, and
- whether the patient objects to having the treatment.

4.3 Some preliminary submissions suggest that these consent requirements can be confusing.[1]

4.4 In this Chapter, we consider whether the consent requirements need changing. In particular we look at:

- the different categories of treatment
- the definition of "person responsible"
- the consent required for sterilisation treatment
- advance care directives, and
- the offence of treating without authorisation.

Categories of treatment

Special treatment

What is special treatment?

4.5 "Special treatment" is considered the most invasive or risky kind of treatment and therefore has the most stringent consent requirements. Special treatment includes treatment that:

- is intended or reasonably likely to render the patient permanently infertile (also known as sterilisation)
- has not yet gained the support of a substantial number of specialists in the relevant practice area
- terminates a pregnancy (also known as abortion)
- is in the nature of a vasectomy or tubal occlusion, or
- involves using an aversive stimulus (that is, using unpleasant events in therapy to control a person's behaviour).[2]

4.6 However, none of the above is considered special treatment if it is given in the course of a clinical trial.[3] We discuss clinical trials in Chapter 5. We consider the specific issue of the consent required for sterilisation later in this Chapter.[4]

Who can consent?

4.7 The NSW Civil and Administrative Tribunal ("Tribunal") can consent to special treatment. Before giving consent, the Tribunal must be satisfied that it is appropriate

1. See, eg, Medical Insurance Group Australia, *Preliminary Submission PGA16*, 3–4.
2. *Guardianship Act 1987* (NSW) s 33(1) definition of "special treatment"; *Guardianship Regulation 2016* (NSW) cl 9.
3. *Guardianship Act 1987* (NSW) s 33(1).
4. See [4.47]-[4.53] .

for the treatment to be carried out. It must take into account certain matters relating to the treatment itself (for example, the nature and effect of the treatment)[5] and the objects of Part 5 of the *Guardianship Act*. It must also consider the views of:

- the patient
- the person proposing the treatment, and
- any persons responsible for the patient.

The Tribunal must be satisfied that the treatment is the most appropriate form of treatment for promoting and maintaining the patient's health and wellbeing.[6]

4.8 For most special treatments, the Tribunal must also be satisfied the treatment is necessary:

- to save the patient's life, or
- to prevent serious damage to the patient's health.[7]

4.9 For certain types of special treatment, including experimental treatment, the Tribunal must instead be satisfied that:

- the treatment is the only or most appropriate way of treating the patient
- the treatment is manifestly in the patient's best interests, and
- any relevant National Health and Medical Research Council guidelines have been complied with.[8]

4.10 The patient's guardian can also consent to special treatment, but only if:

- the Tribunal has previously consented to the treatment and has authorised the guardian to consent to its continuation or further similar treatment, and
- the proposed treatment will promote or maintain the patient's health and wellbeing.

Before consenting to the treatment, the guardian must have regard to the views of the patient and the objects of Part 5.[9]

Effect of the patient's objection

4.11 A guardian's consent has no effect if the person carrying out or supervising the treatment is aware, or ought to be aware, that the patient objects, unless:

- the patient has minimal or no understanding of what the treatment entails, and
- the treatment will cause the patient no distress or the distress is likely to be reasonably tolerable and only transitory.[10]

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5. For the full list of matters to be considered see [4.34], below.
6. *Guardianship Act 1987* (NSW) s 44(3), s 32, s 45(1).
7. *Guardianship Act 1987* (NSW) s 45(2).
8. *Guardianship Act 1987* (NSW) s 45(3).
9. *Guardianship Act 1987* (NSW) s 36(2), s 45A(1)–(2), s 46(2)(b), s 40(3).

When consent is not needed

4.12 Special treatment can be carried out without consent if the doctor or dentist thinks urgent treatment is needed:

- to save the patient's life, or
- to prevent serious damage to the patient's health.[11]

Question 4.1: Special treatment

(1) Is the definition of special treatment appropriate? Should anything be added? Should anything be taken out?

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

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

(4) In what circumstances could special treatment be carried out without consent?

Major treatment

What is major treatment?

4.13 Major treatment is a treatment that includes:

- giving a long-acting injectable hormone for contraception or to regulate menstruation
- giving an addictive drug
- giving a general anaesthetic or other sedative (with some exceptions)
- any treatment used to stop menstruation
- giving a restricted substance to affect the central nervous system (with some exceptions)
- any treatment involving substantial risk to the patient of death, brain damage, paralysis, permanent loss of organ or limb function, permanent disfigurement or scarring, exacerbation of conditions being treated, an unusually prolonged period of recovery, a detrimental change of personality or a high level of pain or stress
- testing for HIV
- any treatment intended or likely to result in the removal of all teeth, or
- any treatment likely to impair significantly for an indefinite or prolonged period the patient's ability to chew food.

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10. *Guardianship Act 1987* (NSW) s 46(4).
11. *Guardianship Act 1987* (NSW) s 37(1)(a)–(b).

4.14 These treatments are not considered major treatments if they are given in the course of a clinical trial or if they also meet the definition of a special treatment.[12]

Who can consent?

4.15 The Tribunal and the person responsible for the patient can consent to major treatment.[13]

4.16 All of the factors at [4.7], above, that the Tribunal must consider before consenting to special treatment it must also consider before consenting to major treatment.

4.17 Before a person responsible gives consent they must consider certain matters relating to the treatment itself (for example, the nature and effect of the treatment), the patient's views and the objects of Part 5. If the proposed treatment is to be carried out for any other purpose than promoting or maintaining the health and wellbeing of the patient, the consent will have no effect.[14]

Effect of the patient's objection

4.18 The consent of the person responsible has no effect if the person carrying out or supervising the treatment is aware, or ought to be aware, that the patient objects, unless:

- the person responsible is a guardian and the Tribunal has given them the authority to override the patient's objection, and
- the guardian is satisfied that the proposed treatment is manifestly in the patient's best interests

or

- the patient has minimal or no understanding of what the treatment entails, and
- the treatment will cause the patient no distress or the distress is likely to be reasonably tolerable and only transitory.[15]

When consent is not needed

4.19 Major treatment can be carried out without consent if the doctor or dentist thinks urgent treatment is needed:

- to save the patient's life
- to prevent serious damage to the patient's health, or
- to prevent the patient from suffering or continuing to suffer significant pain or distress.[16]

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12. *Guardianship Act 1987* (NSW) s 33(1) definition of "major treatment"; *Guardianship Regulation 2016* (NSW) cl 10–11.
13. *Guardianship Act 1987* (NSW) s 36(1).
14. *Guardianship Act 1987* (NSW) s 40(2)–(3), s 46(2)(b).
15. *Guardianship Act 1987* (NSW) s 46(3)–(4), s 46A.
16. *Guardianship Act 1987* (NSW) s 37(1).

Question 4.2: Major treatment

(1) Is the definition of major treatment appropriate? Should anything be added? Should anything be taken out?

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

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

(4) In what circumstances could major treatment be carried out without consent?

Minor treatment

What is minor treatment?

4.20 Minor treatment is any treatment falling within the definition of "medical and dental treatment" but that is not special treatment, major treatment or treatment as part of a clinical trial.[17]

Who can consent?

4.21 The Tribunal or the person responsible can consent to minor treatment.[18]

4.22 All of the factors at [4.7], above, that the Tribunal must consider before consenting to special and major treatment it must also consider before consenting to minor treatment.

4.23 The matters the person responsible must consider before consenting to minor treatment are identical to the matters they must consider before consenting to major treatment: see [4.17] above.

Effect of the patient's objection

4.24 The effect of the patient's objection to minor treatment is identical to the effect of a patient's objection to major treatment: see [4.18] above.

17. *Guardianship Act 1987* (NSW) s 33(1) definition of "minor treatment".
18. *Guardianship Act 1987* (NSW) s 36(1).

When consent is not needed

4.25 Minor treatment can be carried out without consent if the doctor or dentist thinks urgent treatment is needed:

- to save the patient's life
- to prevent serious damage to the patient's health, or
- to prevent the patient from suffering or continuing to suffer significant pain or distress

or

- there is no person responsible, or they cannot be contacted, or they are unwilling to make a decision, and
- the doctor or dentist certifies in writing that:
  - the treatment is necessary
  - the form of treatment will be the most successful at promoting the patient's health and wellbeing, and
  - the patient does not object to the treatment.[19]

Question 4.3: Minor treatment

(1) Is the definition of minor treatment appropriate? Should anything be added? Should anything be taken out?

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

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

(4) In what circumstances could minor treatment be carried out without consent?

Treatment that is not medical or dental treatment

4.26 Treatment that falls outside the Part 5 regime does not require consent. However, nothing in Part 5 prevents the Tribunal, a person responsible for the patient or a guardian from giving consent.[20]

Question 4.4: Treatment that is not medical or dental treatment

Does the *Guardianship Act NSW* (1987) deal with treatments that fall outside of the Part 5 regime adequately and clearly?

19. *Guardianship Act 1987* (NSW) s 37.
20. *Guardianship Act 1987* (NSW) s 46(5).

Question 4.5: Categories of treatment as a whole

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

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

Person responsible

4.27 Under Part 5 of the *Guardianship Act*, a person responsible can consent to major and minor treatment for a person who lacks decision-making capacity.[21]

4.28 If the patient is under the age of 18, the person responsible is someone who has parental responsibility for them. In most other cases, the person responsible is whoever sits at the top of the hierarchy set out in the legislation. That hierarchy is, in descending order:

(a) the patient's guardian (if any), who has been appointed with the power to give consent for medical and dental treatments

(b) the patient's spouse (if their relationship is close and continuing and the spouse is not under guardianship)

(c) a person who has care of the patient, and

(d) a close friend or relative of the patient.[22]

4.29 A "close friend or relative" is defined as a person who has both a close personal relationship with the patient through frequent personal contact and a personal interest in their welfare, on an unpaid basis. The Tribunal can issue guidelines providing more detail about who they will consider a close friend or relative.[23] The Tribunal has not issued any such guidelines.

4.30 An eligible person may, in writing, decline to take on the role of person responsible. Alternatively, an expert can certify that a person is not capable of carrying out the functions required of a person responsible. In either case, the next person in the hierarchy may assume the role.[24]

4.31 Based upon the wording of the hierarchy, we can envisage situations where it might be unclear who the person responsible is. For example, if there is more than one guardian, or more than one close friend or relative, how does a doctor decide who the person responsible is? If they can all be the person responsible and they disagree with each other, whose decision prevails?

4.32 One solution is to make clearer in the legislation who the decision-maker is in any given scenario. Another solution is to set out how disputes between two or more eligible decision-makers should be resolved. In Queensland if two eligible substitute

21. *Guardianship Act 1987* (NSW) s 36(1)(a).
22. *Guardianship Act 1987* (NSW) s 33A(2), s 33A(4).
23. *Guardianship Act 1987* (NSW) s 3E.
24. *Guardianship Act 1987* (NSW) s 33A(5).

decision-makers disagree and the disagreement cannot be resolved by mediation, the Queensland Public Guardian can make the decision.[25] In the Australian Capital Territory ("ACT") disputes between health attorneys can be referred to the ACT Public Trustee and Guardian.[26]

4.33 Council on the Ageing NSW submits that requiring a person responsible to revoke their authority in writing may provide protection for medical practitioners but it can cause stress and compound grief for family members. The Council recommends that NSW adopt a similar procedure to Queensland's where responsibility automatically passes to the next person in the hierarchy if the previous person is not "readily available".[27]

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?

Matters relating to treatment that a decision-maker must consider before giving consent

4.34 Before they can consent to a treatment, the *Guardianship Act* requires the relevant decision-maker (either the Tribunal or the person responsible) to consider:

- the objects of Part 5
- the grounds on which it is alleged the person is incapable of giving consent
- the particular condition requiring treatment
- any available alternative treatment options
- the general nature and effect of all treatment options
- the nature and degree of any significant risks associated with the treatment, and
- the reasons for which it is proposed to carry out the treatment.[28]

Question 4.7: Factors that should be considered before consent

Are the factors a decision-maker must consider before consenting to treatment appropriate? If not, what could be added or removed?

25. *Guardianship and Administration Act 2000* (Qld) s 42(1).
26. *Guardianship and Management of Property Act 1991* (ACT) s 32I.
27. Council on the Ageing NSW, *Preliminary Submission PGA10*, 7; *Powers of Attorney Act 1998* (Qld) s 63.
28. *Guardianship Act 1987* (NSW) s 32, s 40(2)–(3), s 42(2).

Requirement that consent requests and consents be in writing

4.35 A request from a treatment team for consent to carry out a minor medical or dental procedure should be in writing. However, if it is not practicable for the request to be made in writing, or if the person responsible does not require the request to be in writing, a verbal request is sufficient.[29]

4.36 Similarly, a person responsible must give their consent for minor treatment in writing, unless this is not practicable or the person carrying out the treatment does not require it. In such cases, they can give verbal consent.[30]

4.37 Consent to major treatment must be requested and given in writing, unless there is an urgent need to carry out the treatment. In that case, both request and consent can be provided orally.[31]

4.38 One stakeholder submits that written requests and consents are impractical in certain situations, such as hospitals. Nor are they necessary given the record-keeping requirements hospitals already have.[32]

Question 4.8: Requirement that consent requests and consents be in writing

Is the requirement that consent requests and consents must be in writing appropriate? If not, what arrangements should be in place?

Supported decision-making for medical and dental treatment decisions

4.39 Part 5 of the *Guardianship Act* sets out a substitute decision-making regime that determines who can consent to medical or dental treatment when the patient is incapable of giving consent.

4.40 Some places have laws that allow a person to be formally appointed to support a patient to make their own decisions about medical and dental treatment in appropriate circumstances. These are in addition to the laws that allow substitute decision-makers to be appointed.

4.41 In Question Paper 2 we considered different types of alternative decision-making models and their features. We talked about the growing preference around the world for supported decision-making. Supported decision-making emphasises that all people have the right to make decisions for themselves but recognises that some people may need or want support in reaching their decision. You may want to revisit Question Paper 2 before responding to Question 4.9.

4.42 In Ireland, Alberta and British Columbia (Canada) and Texas (United States), a supporter can be appointed to help a person make decisions about their healthcare.[33] Ireland and Alberta also allow co-decision-makers to be appointed.[34]

29. *Guardianship Regulation 2016* (NSW) cl 12(1).
30. *Guardianship Regulation 2016* (NSW) cl 13(1).
31. *Guardianship Regulation 2016* (NSW) cl 12(2), cl 13(2).
32. Medical Insurance Group Australia, *Preliminary Submission PGA16,* 4.

4.43 Supporter-like roles already exist in the mental health laws of some states and territories. For example, in the ACT and Western Australia a nominated person can help the patient ensure that their interests, views and wishes are respected.[35]

4.44 Victoria recently passed legislation (due to commence by March 2018) which allows for the formal appointment of medical supporters. Under the new laws, a person can appoint one person to support them to "make, communicate and give effect to" their medical treatment decisions, and represent their interests in relation to medical treatment. Appointments must be in writing and conform to various formal requirements.[36]

4.45 Submissions to the Australian Law Reform Commission Report *Equality, Capacity and Disability in Commonwealth Laws* suggested that a supported decision-making framework would be more likely to result in health care decisions that accord with an individual's personal beliefs and values.[37]

4.46 If NSW were to introduce a formal supported decision-making model for medical and dental decisions, it would need to consider carefully how this model interacts with the informal support model adopted in the *Mental Health Act 2007* (NSW). This model requires that every effort is made to involve the patient in the development of treatment and recovery plans and to consider their views and expressed wishes.[38]

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

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

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

Sterilisation

Consent for sterilisation

4.47 Treatment that is intended, or reasonably likely, to make a person permanently infertile (sterilisation treatment) is defined as a type of special treatment. Only the Tribunal can authorise such treatment.[39]

33. *Assisted Decision-Making (Capacity) Act 2015* (Ireland) s 10(1); *Adult Guardianship and Trusteeship Act 2008* (Alberta) s 1(bb), s 3–4, s 9; *Representation Agreement Act 1996* (British Columbia) s 7(1)(c); *Supported Decision-Making Agreement Act*, 1357 Estates Code (Texas) § 1357.002(3), § 1357.051.
34. *Assisted Decision-Making (Capacity) Act 2015* (Ireland) s 17; *Adult Guardianship and Trusteeship Act 2008* (Alberta) s 11–13, s 17, s 22. For a discussion of the differences between supported decision-making and co-decision-making, see NSW Law Reform Commission, *Decision-Making Models*, Review of the Guardianship Act 1987 Question Paper 2 (2016) ch 2.
35. See, eg, *Mental Health Act 2014* (WA) s 263.
36. *Medical Treatment Planning and Decisions Act 2016* (Vic) s 31–32.
37. Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report 124 (2014) [10.52].
38. Mental Health Review Tribunal, *Preliminary Submission PGA21*, 7; *Mental Health Act 2007* (NSW) s 68(h).
39. *Guardianship Act 1987* (NSW) s 33(1) definition of "special treatment", s 36(1)(b).

4.48 Some stakeholders think that substitute consent mechanisms for sterilisation procedures should be banned altogether.[40] The World Health Organization ("WHO") has said "any procedure resulting in sterilization must be provided on the basis of full, free and informed consent".[41]

4.49 The Commonwealth Senate Community Affairs References Committee ("References Committee") considered these issues in its inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia. It concluded:

> An outright ban of non-therapeutic sterilisation procedures without consent potentially denies the rights of persons with disabilities to access all available medical support on an equal basis with persons without a disability. It is a "one size fits all" solution to a complex problem. An outright ban removes the focus from the needs and interests of the individual, placing it instead on generic notions of what is best for persons with disabilities as an homogenous group.[42]

4.50 Nonetheless, the References Committee noted that Australia's commitment to the United Nations *Convention on the Right of Persons with Disabilities* requires governments "to ensure that substitute decision-making occurs only as a last resort and only with all necessary safeguards".[43] It made a number of recommendations including:

- a ban on the involuntary sterilisation of people who have the capacity to consent "with appropriate decision-making support"
- a ban on the irreversible sterilisation of people who might develop a capacity to consent in the future, and
- a uniform "best protection of rights" test (to replace "best interests" tests) that explicitly refers to protecting an individual's rights and maintaining "future options and choices".[44]

4.51 The Australian Guardianship and Administration Council developed the *Protocol for Special Medical Procedures (Sterilisation*) ("Protocol") in 2009. The decision-making principles in the Protocol include:

- upholding a person's right to participate, to the greatest extent practicable, in decisions affecting their life
- considering the express wishes of the person, to the extent the person is capable of expressing their wishes, and
- if there is a choice between a more or less intrusive or permanent form of treatment, adopting the less intrusive way unless it is, or would be, unsatisfactory.[45]

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40. See, eg, NSW Council for Civil Liberties, *Preliminary Submission PGA19*, 3–4.
41. World Health Organization, *Eliminating Forced, Coercive and otherwise Involuntary Sterilization: An Interagency Statement* (2014) 6.
42. Australia, Senate, Community Affairs References Committee, *Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013) [4.37].
43. Australia, Senate, Community Affairs References Committee, *Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013) [4.45].
44. Australia, Senate, Community Affairs References Committee, *Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013) rec 6, rec 7, rec 11.

All Australian states and territories have adopted the Protocol.[46]

4.52 We understand the Tribunal considers the Protocol in appropriate circumstances. The principles share considerable common ground with the general principles of the *Guardianship Act*.[47] While the principles of the Protocol are applied in substitute decision-making arrangements across Australia, they are also entirely consistent with a supported decision-making approach.

4.53 There may be further ways in which the *Guardianship Act* could encourage a supported decision-making approach in relation to consent for sterilisation treatment.

Question 4.10: Consent for sterilisation

(1) Who, if anyone, should have the power to consent to a sterilisation procedure?

(2) In what ways, if any, could the *Guardianship Act 1987* (NSW) better uphold the right of people without decision-making capacity to participate in a decision about sterilisation?

Preconditions for consent to sterilisation

4.54 Before giving consent, the Tribunal must be satisfied that sterilisation is:

- the most appropriate form of treatment for promoting and maintaining the patient's health and wellbeing, and
- necessary to save the patient's life or prevent serious damage to the patient's health.[48]

4.55 Some people think the circumstances in which the Tribunal can approve sterilisation are too narrow. One stakeholder submits that the *Guardianship Act* prevents the Tribunal from granting consent for a hysterectomy or ablation in cases where the patient's quality of life is being severely affected by menstruation. The submission argues that the law should change to make it easier for the Tribunal to consent to treatment in these cases.[49] Other stakeholders think the Tribunal's powers are too broad.[50]

4.56 Preconditions for consent to sterilisation vary between states and territories. They include that:

- sterilisation is medically necessary[51]

45. Australian Guardianship and Administration Council, *Protocol for Special Medical Procedures (Sterilisation)* (2009) [4.1].
46. Australia, Senate, Community Affairs References Committee, *Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013) [3.53].
47. *Guardianship Act 1987* (NSW) s 4.
48. *Guardianship Act 1987* (NSW) s 44, s 45(2).
49. J Carter, *Preliminary Submission PGA03.*
50. See, eg, NSW Council for Civil Liberties, *Preliminary Submission PGA19*, 3–4.
51. See, eg, *Guardianship and Administration Act 1993* (SA) s 61(2)(a).

- the person is likely to be sexually active and sterilisation is the only method of contraception that can be successfully applied[52]
- the procedure is in the patient's best interests[53]
- stopping the patient's menstrual cycle is in her best interests, and sterilisation is the only way to deal with problems associated with menstruation[54]
- the sterilisation cannot reasonably be postponed and the adult is unlikely to gain capacity in the foreseeable future[55]
- the Tribunal has taken into account any alternative forms of health care, including other sterilisation procedures, which are available, or likely to become available,[56] and
- the Tribunal has taken into account the nature and extent of any significant risks associated with the treatment.[57]

Question 4.11: Preconditions for consent to sterilisation

What matters should the NSW Civil and Administrative Tribunal be satisfied of before making a decision about sterilisation?

Matters that should not be taken into account

4.57 The References Committee discussed matters that it thought should specifically *not* be taken into account in the approval of sterilisation procedures. These included:

- the risk of pregnancy as a result of sexual abuse, and
- assessments of the person's current or hypothetical capacity to care for children.[58]

4.58 Queensland law specifies that sterilisation is not medically necessary if it is proposed for eugenic reasons or to remove the risk of pregnancy resulting from sexual abuse.[59]

Question 4.12: Matters that should not be taken into account in sterilisation decisions

52. *Guardianship and Administration Act 1993* (SA) s 61(2)(b)(iii)(A); *Guardianship and Administration Act 2000* (Qld) s 70(1)(a)(ii).
53. *Guardianship and Administration Act 1986* (Vic) s 42E(c); *Guardianship and Administration Act 1990* (WA) s 63(1); *Guardianship and Administration Act 1995* (Tas) s 45(1)(c).
54. *Guardianship and Administration Act 1993* (SA) s 61(2)(b)(iii)(B); *Guardianship and Administration Act 2000* (Qld) s 70(1)(a)(iii).
55. *Guardianship and Administration Act 2000* (Qld) s 70(1)(b)–(c).
56. *Guardianship and Administration Act 2000* (Qld) s 70(3)(a).
57. *Guardianship and Administration Act 2000* (Qld) s 70(3)(b).
58. Australia, Senate, Community Affairs References Committee, *Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013) rec 5, rec 19.
59. *Guardianship and Administration Act 2000* (Qld) s 70(2).

(1) Is there anything the NSW Civil and Administrative Tribunal should *not* take into account when deciding about sterilisation?

(2) Should these be stated expressly in the *Guardianship Act 1987* (NSW)?

Advance care directives

4.59 An advance care directive states a person's wishes and preferences for a time when they can no longer consent to care, including end-of-life care. A person can make a directive either orally or in writing. A valid directive will take priority over the decisions of an alternative decision-maker. A person might also use an advance care directive to nominate an alternative decision-maker to support them to make decisions or to make decisions for them.

4.60 Unlike most other Australian states and territories, NSW legislation does not explicitly recognise advance care directives. Rather, advance care directives have legal authority under the common law.[60] The NSW Supreme Court has held that the *Guardianship Act* recognises advance care directives "to some extent and for some purposes"[61] because of the wording of s 33(3) of the Act:

> For the purposes of this Part, a person shall be taken to object to the carrying out of medical or dental treatment:
>
> (a) if the person indicates (by whatever means) that he or she does not want the treatment to be carried out, or
>
> (b) if the person:
>
> (i) has previously indicated, in similar circumstances, that he or she did not then want the treatment to be carried out, and
>
> (ii) has not subsequently indicated to the contrary.

4.61 In 2009 the Supreme Court set out some general principles about advance care directives:

- An adult can make an advance care directive specifying that they do not wish to receive medical treatment, or medical treatment of a particular kind.
- If the adult makes an advance care directive at a time when they have capacity, and it "is clear and unambiguous, and extends to the situation at hand", the advance care directive must be respected.
- A medical practitioner or hospital should apply to the court for help if there is genuine and reasonable doubt about the validity of an advance care directive or whether it applies to a situation at hand.

60. This includes advance care directives written outside NSW. See NSW Health, "Advance Care Plans and the Law" <http://healthlaw.planningaheadtools.com.au/advance-care-plans-and-the-law/> (retrieved 28 February 2017).

61. *Hunter and New England Area Health Service v A* [2009] NSWSC 761, 74 NSWLR 88 [39].

- If a medical practitioner or hospital promptly applies to the court for help, they can continue to administer emergency treatment until the court hands down its decision.
- An adult does not need to be told of the consequences of refusing the medical treatment in order for their advance care directive to be valid, "[n]or does it matter that the person's decision is based on religious, social or moral grounds rather than upon (for example) some balancing of risk and benefit".
- A capable adult's decision does not need to be supported by "any discernible reason" so long as the advance care directive is made voluntarily and in the absence of any vitiating factors such as misrepresentation or undue influence.[62]

Should NSW legislation specifically recognise advance care directives?

4.62 One view is that the lack of legislative certainty creates a barrier to the wider uptake of advance care directives. For example, it can be difficult to work out the relationship between an advance care directive and the decision-making powers of substitute decision-makers. Council on the Ageing NSW says

> many hospitals and health care providers still do not understand that if a person has completed an Advance Care Directive which meets the current situation, it is legally binding and takes precedence over the decisions of an Enduring Guardian, other "person responsible", other family member or treating medical practitioner.[63]

4.63 Another view is that NSW does not need statutory provisions because the case law gives ample guidance about advance care directives. The NSW Government has said that in such a nuanced area of law, legislation could never be flexible enough to deal with individual cases. It has also said that in other states and territories where advance care directives are legislated, there is no evidence to suggest an increase in the use of directives or a marked difference in health care practice.[64]

4.64 A number of preliminary submissions support legislation that explicitly addresses advance care directives.[65] If NSW decides to recognise advance care directives explicitly in legislation, we need to decide whether we include guidance in the *Guardianship Act* or in another act and what the elements of a statutory framework should be.

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?

62. *Hunter and New England Area Health Service v A* [2009] NSWSC 761, 74 NSWLR 88 [40].
63. Council on the Ageing NSW, *Preliminary Submission PGA10*, 7.
64. NSW Government, *Legislative Council Standing Committee on Social Issues, Substitute Decision-Making for People Lacking Capacity: Government Response* (2011) rec 35, citing The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives* (2011).
65. See, eg, Council on the Ageing NSW, *Preliminary Submission PGA10,* 7; Medical Insurance Group Australia, *Preliminary Submission PGA16,* 3; Australian Centre for Health Law Research, *Preliminary Submission PGA47*, 3.

Possible elements of a statutory framework

Who can make an advance care directive?

4.65 Under common law, a "capable adult" can make an advance care directive so long as they make it voluntarily and in the absence of any factors that could invalidate it, such as misrepresentation or undue influence.[66]

4.66 This definition is broadly similar to those in the legislation of other states and territories. For example, in South Australia, a "competent adult" can make an advance care directive if they understand what an advance care directive is and the consequences of making one.[67] New legislation in Victoria that will come into force by March 2018 allows any person to make an advance care directive provided they understand the nature and effect of each statement in the directive.[68]

4.67 Queensland also requires the adult making the directive to understand that the directive only operates while the person has impaired capacity and that they can revoke it at any time, while they still have capacity for the matters covered.[69]

Question 4.14: Who can make an advance care directive

Who should be able to make an advance care directive?

Form of an advance care directive

4.68 In NSW, there are no requirements for the form an advance care directive can take. In the ACT, an adult can make a direction orally, in writing, or "in any other way".[70] In other states and territories requirements include that the directive is in writing,[71] is in English,[72] is in an approved form,[73] is signed and witnessed,[74] and is accompanied by a doctor's certificate saying the person appears to have decision-making capacity.[75]

Question 4.15: Form of an advance care directive

What form should an advance care directive take?

66. *Hunter and New England Area Health Service v A* [2009] NSWSC 761, 74 NSWLR 88 [40].
67. *Advance Care Directives Act 2013* (SA) s 11(1).
68. *Medical Treatment Planning and Decisions Act 2016* (Vic) s 13(a)(ii).
69. *Powers of Attorney Act 1998* (Qld) s 42(1)(c).
70. *Medical Treatment (Health Directions) Act 2006* (ACT) s 7(2).
71. See, eg, *Advance Personal Planning Act* (NT) s 9(2)(b).
72. See, eg, *Medical Treatment Planning and Decisions Act 2016* (Vic) s 16(1)(a).
73. See, eg, *Guardianship and Administration Act 1990* (WA) s 110Q(1)(a).
74. See, eg, *Guardianship and Administration Act 1990* (WA) s 110Q(1)(c)–(e).
75. See, eg, *Powers of Attorney Act 1998* (Qld) s 44(6)–(7).

Matters an advance care directive can cover

4.69 **Ability to give instructions about future health care.** Some states distinguish between the instructions a person can give in an advance care directive about:

- receiving life-sustaining treatment, and
- stopping or withholding life-sustaining treatment.

4.70 In Queensland, for example, more stringent conditions apply to instructions to stop or withhold life-sustaining measures. For example, the instructions will not operate unless the person has a terminal illness and is reasonably expected to die within a year or is in a persistent vegetative state.[76]

4.71 In South Australia, an advance care directive cannot be used to "compel a health practitioner to provide a particular form of health care to a person":

> Whilst a person can indicate his or her wishes in respect of the health care he or she wishes to receive, ultimately the question of what form of health care should be provided to a patient is a matter for the health practitioner to decide (however, a person is entitled to refuse health care of any kind, or to require it to be stopped, including health care that saves or prolongs his or her life).[77]

4.72 **Ability to give instructions about matters other than health care.** In South Australia an advance care directive can cover residential and accommodation matters and personal affairs as well as health care.[78]

4.73 **A general statement about the person's views, wishes and beliefs.** Northern Territory legislation specifically allows an advance care directive to include a statement outlining the adult's views, wishes and beliefs that should be the basis for decisions that are made for them.[79] South Australia allows a person to express in a directive what constitutes their "quality of life".[80]

4.74 Victoria's new laws will allow the person to include a "values directive", defined as a statement of the person's "preferences and values as the basis on which the person would like any medical decisions to be made". Such a statement can include "medical treatment outcomes that the person regards as acceptable".[81]

4.75 **Ability to appoint a substitute decision-maker to make health care decisions.** In NSW, a person may already appoint someone else to make health and medical decisions for them when they lose capacity. They can do this through an enduring guardianship appointment. Other states allow adults to use advance care directives to appoint one or more people to make future health care decisions on their behalf.[82] In Queensland, a direction in an advance care directive takes priority over a general or specific power for health matters given to an attorney in a power of attorney appointment.[83]

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76. *Powers of Attorney Act 1998* (Qld) s 36(2).
77. *Advance Care Directives Act 2013* (SA) s 6(1).
78. *Advance Care Directives Act 2013* (SA) s 11(3).
79. *Advance Personal Planning Act* (NT) s 8(1)(b).
80. *Advance Care Directives Act 2013* (SA) s 10(b).
81. *Medical Treatment Planning and Decisions Act 2016* (Vic) s 6(2), s 12(2)(b).
82. *Powers of Attorney Act 1998* (Qld) s 35(1)(c); *Advance Personal Planning Act* (NT) s 16.
83. *Powers of Attorney Act 1998* (Qld) s 35(3).

4.76 In South Australia, a person can appoint a substitute decision-maker in an advance care directive, however, before they can make a decision, the substitute decision-maker must produce a certified or authorised copy of the directive if a medical practitioner requests it.[84]

4.77 In the ACT, if an adult loses capacity and a guardian is appointed to make medical decisions for them, the guardian must exercise their power in a way that is consistent with the patient's health care direction, unless it is not reasonable to do so.[85] On the other hand, if an adult makes an enduring power of attorney appointment to deal with health care matters, this revokes any inconsistent health care directions the patient has previously made.[86]

4.78 In the Northern Territory, appointed decision-makers cannot make decisions about certain restricted health matters, including sterilisation, terminating a pregnancy and removing non-regenerative human tissue.[87] The new Victorian law will allow adults to appoint someone to act as their "medical treatment decision-maker". Medical treatment decision-makers may be asked to make decisions about medical treatment and medical research.[88]

Question 4.16: Matters an advance care directive can cover

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

When an advance care directive is invalid

4.79 Some laws specify the circumstances in which an advance care directive will be invalid. Examples include:

- the person did not have the capacity to make the directive,[89] did not make it voluntarily or made it because of inducement or coercion[90]
- at the time the directive was made, the person did not understand the nature of the decision or the consequences of making the decision[91]
- the person relied on incorrect information or made incorrect assumptions when making the directive[92]
- following the directive would mean that a person could avoid mandatory treatment, including mental health treatment[93]

84. *Advance Care Directives Act 2013* (SA) s 24(1)(a), s 21.
85. *Medical Treatment (Health Directions) Act 2006* (ACT) s 18.
86. *Medical Treatment (Health Directions) Act 2006* (ACT) s 19(3).
87. *Advance Personal Planning Act* (NT) s 25.
88. *Medical Treatment Planning and Decisions Act 2016* (Vic) s 26–27, pt 4, pt 5.
89. *Powers of Attorney Act 1988* (Qld) s 113(2)(a).
90. *Guardianship and Administration Act 1990* (WA) s 110R(1); *Powers of Attorney Act 1988* (Qld) s 113(2)(c).
91. *Guardianship and Administration Act 1990* (WA) s 110R(2).
92. *Medical Treatment Planning and Decisions Act 2016* (Vic) s 23(b)(ii).
93. *Advance Care Directives Act 2013* (SA) s 12(1)(b), s 12(4).

- circumstances have arisen which the person could not have reasonably anticipated when making the directive, and which would have caused a reasonable person in their position to change their mind about the treatment decision[94]
- part of the directive does not reflect the person's current wishes[95]
- the health care proposed is not consistent with relevant professional standards, or does not reflect current standards of health care[96]
- there are conscientious grounds for a practitioner to refuse to comply with the directive,[97] or
- relying on the directive would cause the person unacceptable pain and suffering, or would otherwise be so "wholly unreasonable" as to justify overriding the person's wishes.[98]

Question 4.17: When an advance care directive should be invalid

In what circumstances should an advance care directive be invalid?

Offences

4.80 It is an offence under the *Guardianship Act* to carry out medical or dental treatment on a patient without the required consent, authorisation or a Supreme Court order. In the case of special treatment or treatment in the course of a clinical trial, the maximum penalty is imprisonment for seven years. In the case of minor or major treatment the maximum penalty is imprisonment for one year or $1,100 or both.[99]

4.81 The References Committee recommended an offence be created for people who take, attempt to take, or knowingly assist a person to take, a person with a disability overseas to obtain a sterilisation procedure.[100]

Question 4.18: Part 5 offences

(1) Are the various offences of treating without authorisation and the maximum penalties that apply appropriate and effective?

(2) Is there a need for any other offences relating to medical and dental treatment?

94. *Guardianship and Administration Act 1990* (WA) s 110S(3).
95. *Advance Care Directives Act 2013* (SA) s 36(2)(b).
96. *Advance Care Directives Act 2013* (SA) s 36(3).
97. *Advance Care Directives Act 2013* (SA) s 37.
98. *Advance Personal Planning Act* (NT) s 41(3)(b).
99. *Guardianship Act 1987 (NSW)* s 35; *Crimes (Sentencing Procedure) Act 1999* (NSW) s 17.
100. Australia, Senate, Community Affairs References Committee, *Involuntary or Coerced Sterilisation of People with Disabilities in Australia* (2013) rec 28.

5. Clinical trials

In brief

In this Chapter, we consider the question of who can authorise a person's participation in a clinical trial and in what circumstances.

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5.1 The *Guardianship Act 1987* (NSW) ("*Guardianship Act*") sets out when and how people who lack decision-making capacity may participate in clinical trials. Stricter consent requirements apply to clinical trials than to other forms of medical or dental treatment.

5.2 Across Australia, researchers who run clinical trials must gain approval from an ethics council and comply with national guidelines in order to qualify for funding.[1] In NSW, researchers must also gain the approval of the NSW Civil and Administrative Tribunal ("Tribunal") to run clinical trials involving patients who lack the capacity to consent.[2] Researchers must then gain consent for each participant from either the Tribunal or the "person responsible".[3]

5.3 One of the key issues is how to preserve the autonomy of the person who lacks decision-making capacity and protect them from exploitation while also promoting equal access to the potential benefits of clinical research and treatment. A particular question is what weight should be given to the person's views and wishes, especially when they do not want to participate in a clinical trial. We seek your ideas about how these considerations could be balanced.

Overview of the law in NSW

5.4 A substitute decision-maker can consent to a person who lacks decision-making capacity participating in a clinical trial. The *Guardianship Act* sets out two distinct approval processes for clinical trials – the first for the clinical trial itself and the second for the patient's participation in that trial.

1. Australia, National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research* (2007) (updated May 2015).
2. *Guardianship Act 1987* (NSW) s 45AA.
3. *Guardianship Act 1987* (NSW) s 45AA(4), s 45AB. On who can be a "person responsible", see Chapter 4.

5.5 The Tribunal can approve a clinical trial which seeks to include the participation of people who lack decision-making capacity if it is satisfied that:

- the drugs or techniques being tested are intended to cure or improve the patients' condition
- the trial will not involve any known substantial risk to the patients (or no greater risks than those associated with relevant existing treatments)
- safety and ethical considerations make it appropriate that the trial be available to patients with the relevant condition, even if those patients cannot consent to taking part
- it is in the patients' best interests to take part in the trial – having regard to the potential benefits and risks, and
- a relevant ethics committee has approved the trial and it complies with the relevant guidelines.[4]

5.6 If the Tribunal decides to approve the clinical trial, it must then decide who should consent to a particular person's participation. The Tribunal can decide either to continue to make decisions about treatment during the trial, or to delegate this power to the persons responsible if satisfied they have sufficient information about the trial.[5]

5.7 Division 3 of the *Guardianship Act* sets out what the persons responsible must take into account before consenting to treatment in the course of a clinical trial. Division 4 sets out what the Tribunal must consider. The requirements include considering the views (if any) of the patient and matters specific to the treatment itself (for example, the general nature and effect of the treatment).[6]

Definition of "clinical trial"

Scope of the definition

5.8 The *Guardianship Act* defines a clinical trial as "a trial of drugs or techniques that necessarily involves the carrying out of medical or dental treatment on the participants in the trial".[7]

5.9 For medical and dental treatment falling outside this definition, less stringent consent requirements apply.

5.10 The Appeal Panel of the Tribunal recently observed that, read in isolation, the definition of clinical trial

> is extremely broad and could include every test or study relating to the use of drugs or techniques so long as it involves medical treatment, no matter how old, well accepted or widely available the drug or technique might be.[8]

4. *Guardianship Act 1987* (NSW) s 45AA(2).
5. *Guardianship Act 1987* (NSW) s 45AB.
6. *Guardianship Act 1987* (NSW) div 3, div 4.
7. *Guardianship Act 1987* (NSW) s 33(1) definition of "clinical trial".

5.11 However, the Appeal Panel ultimately decided that, when read as a whole, the provisions of Part 5 suggest that a clinical trial refers only to new or untested treatments.[9]

5.12 The broad definition of clinical trial may have resulted in the strict consent requirements that apply to clinical trials being applied in situations where the less stringent requirements applying to other forms of treatment are appropriate. The South Eastern Sydney Local Health District Human Research Ethics Committee says the definition has resulted in comparable trials having different consent requirements simply because one was a trial of drugs or techniques and one was not.[10] NSW Health submits that the definition of clinical trial in the *Guardianship Act* should be reviewed as it is too broad and open to interpretation.[11]

Question 5.1: Definition of "clinical trial"

How should the *Guardianship Act 1987* (NSW) define "clinical trial"?

Should there be more than one category of medical research?

5.13 Other states and territories distinguish between different categories of research and apply different consent regimes to each. In Queensland, stricter safeguards attach to "special medical research or experimental healthcare", which is research intended to gain knowledge about a condition the patient has that may result in significant benefit to the patient or future patients with the same condition.[12]

5.14 The Australian Capital Territory ("ACT") has different consent regimes for "low risk research" that poses no foreseeable risk of harm to the patient (and is not part of a clinical trial)[13] and "medical research", which includes experimental health care and participation in a clinical trial.[14]

5.15 In its preliminary submission, the South Eastern Sydney Local Health District Human Research Ethics Committee suggests we consider whether different consent regimes should operate in NSW "depending upon the nature of the treatment or procedure contemplated, or the degree of risk involved".[15]

5.16 In its review of Victoria's laws, the Victorian Law Reform Commission recommended that the law should distinguish between a medical research procedure that is an adjunct to medical treatment and one that is undertaken for the

8. *Shehabi v Attorney General (NSW)* [2016] NSWCATAP 137 [68].
9. *Shehabi v Attorney General (NSW)* [2016] NSWCATAP 137 [84].
10. South Eastern Sydney Local Health District Human Research Ethics Committee, *Preliminary Submission PGA40* [23].
11. NSW Health, *Preliminary Submission PGA49*, 8.
12. *Guardianship and Administration Act 2000* (Qld) s 72(1)–(2), sch 2 cl 12–13.Compare with s 45AA(2)(a) of the *Guardianship Act 1987* (NSW), which requires the Tribunal to be satisfied that the drugs or techniques that are being tested are intended to cure or alleviate a condition from which the patient suffers.
13. *Powers of Attorney Act 2006* (ACT) s 41A(1) definition of "low-risk research", s 41C.
14. *Powers of Attorney Act 2006* (ACT) s 41A(1) definition of "medical research", s 41D.
15. South Eastern Sydney Local Health District Human Research Ethics Committee, *Preliminary Submission PGA40* [32].

purposes of medical research (that is, not primarily to provide a medical intervention to treat a person's current condition).[16]

Question 5.2: Categories of medical research

(1) Should there be more than one category of medical research?

(2) If so, what should those categories be and what consent regimes should apply to each?

Consent to participate in a clinical trial

Who can consent?

5.17 The Tribunal can approve clinical trials involving patients who lack the capacity to consent.[17] Depending on what the Tribunal has ordered, researchers must then gain consent for each participant from either the Tribunal or the "person responsible".[18]

5.18 In Victoria and the ACT, the relevant tribunal is not involved in the approval process. After an ethics committee has approved the clinical trial, researchers can seek direct consent from a substitute decision-maker.[19]

5.19 When it passed new guardianship laws in 2016, the ACT government decided to bypass the ACT Civil and Administrative Tribunal for three reasons:

- it would place an unnecessary burden on the tribunal in circumstances where there is already a person who has been appointed to make the decision
- it would effectively displace the appointed decision-maker with an unknown person or panel of people, and
- a requirement to seek tribunal consent could discourage medical researchers from undertaking research.[20]

5.20 Allowing substitute decision-making in the context of clinical trials may be a breach of international law. Article 15 of the United Nations *Convention on the Rights of Persons with Disabilities* provides that "no one shall be subjected without his or her free consent to medical or scientific experimentation".[21]

5.21 However, obtaining "free consent" may be difficult where a patient does not understand what the research involves or does not have the means to communicate

16. Victorian Law Reform Commission, *Guardianship*, Final Report 24 (2012) rec 220, [14.46]–[14.49].
17. *Guardianship Act 1987* (NSW) s 45AA(1).
18. *Guardianship Act 1987* (NSW) s 45AA(4), s 45AB.
19. *Guardianship and Administration Act 1986* (Vic) s 42S–42T; *Guardianship and Management of Property Act 1991* (ACT) s 32D, s 33; *Powers of Attorney Act 2006* (ACT) s 41A, s 41C–41D.
20. Explanatory Statement, Powers of Attorney Amendment Bill 2015 (ACT) 2–3.
21. *Convention on the Rights of Persons with Disabilities*, 2515 UNTS 3 (entered into force 3 May 2008) art 15(1). See also *International Covenant on Civil and Political Rights,* 999 UNTS 171 (entered into force 23 March 1976) art 7.

their consent or refusal. It has been argued that, while it is important to protect vulnerable patients from exploitation, safeguards that effectively bar patients from participating in clinical research may lead to undesirable outcomes. O'Neill and Pesiah say:

> The evidence-base for the treatment of many of the conditions which affect cognition and potentially impair capacity (particularly involving older people) is lacking and more research is needed. … Research is also necessary to develop new and improve upon existing treatments to be used to alleviate or cure the conditions that render people permanently incapable of giving a valid consent to their own treatment. Such treatments cannot be proved effective unless they are carried out on those who have the particular conditions the treatment is designed to address. … Thus limiting research to people who are able to decide for themselves would deprive people who lack capacity of proven therapies for the conditions which specifically affect them.[22]

5.22 There are arguably ways to improve our laws to ensure patients have a greater degree of autonomy when it comes to their participation in clinical trials. For example, supported decision-making (discussed in detail in Question Paper 2[23]) could ensure a person has the necessary support to help them make their own decisions and communicate those decisions.

Question 5.3: Who can consent to clinical trial participation

(1) Who should be able to approve a clinical trial?

(2) Who should be able to consent to a patient's participation in a clinical trial if the patient lacks decision-making capacity?

(3) How can the law promote the patient's autonomy in the decision-making process?

Considering the views and objections of the patient

5.23 In NSW, the substitute decision-maker must consider the views (if any) of the patient before consenting to medical treatment that is part of a clinical trial.[24] However, if a patient objects to the treatment, the substitute decision-maker's consent can override that objection in certain circumstances.[25]

5.24 The situation is different in Queensland where the Queensland Civil and Administrative Tribunal cannot consent if the patient objects to participating in special medical research or experimental health care.[26] An objection includes an indication given orally or by conduct.[27] In England and Wales, the *Mental Capacity Act 2005* (UK) similarly provides that nothing can be done to an incapacitated person in a research project if they appear to object.[28] In Scotland, research can

22. N O'Neill and C Pesiah, *Capacity and the Law* (Sydney University Press, 2011) [16.5].
23. NSW Law Reform Commission, *Decision-Making Models*, Review of the Guardianship Act 1987 Question Paper 2 (2016).
24. *Guardianship Act 1987* (NSW) s 40(3)(a), s 44(2)(a)(i).
25. *Guardianship Act 1987* (NSW) s 46(3)–(4), s 46A.
26. *Guardianship and Administration Act 2000* (Qld) s 72(3)(a).
27. *Guardianship and Administration Act 2000* (Qld) sch 4 definition of "object".
28. *Mental Capacity Act 2005* (UK) s 33(2).

only be carried out if the patient "does not indicate unwillingness" to participate in the research.[29]

Question 5.4: Considering the views and objections of patients

(1) If the patient cannot consent, should the decision-maker be required to consider the views of the patient?

(2) What should happen if a patient objects to participating in a clinical trial? Should substitute consent be able to override a patient's objection? If so, in what circumstances?

Other preconditions for consent

5.25 Divisions 3 and 4 of the *Guardianship Act* set out what the persons responsible and the Tribunal must take into account before consenting to treatment in the course of a clinical trial. The requirements include considering the views (if any) of the patient and matters specific to the treatment itself (for example, the general nature and effect of the treatment).[30] The Tribunal must be satisfied that the treatment is the most appropriate form of treatment for promoting and maintaining the patient's health and wellbeing.[31]

5.26 Preconditions that appear in the laws of other places but not explicitly in NSW law include:

- if a potential participant is incapable of giving consent because, for example, they are unconscious, the cause of the incapacity must be a necessary characteristic of the research group[32]
- if a patient's impairment is temporary or episodic, researchers should attempt to seek consent at a time when the patient has decision-making capacity[33]
- the person must have received certain information about the trial (including the risks and benefits) in a way they can understand[34]
- the person's representative must not have received any incentives or financial inducements,[35] and
- it must be essential to the trial that participants lack capacity, and no comparable data can be obtained from people who can give informed consent.[36]

29. *Adults with Incapacity (Scotland) Act 2000* s 51(3)(b).
30. *Guardianship Act 1987* (NSW) div 3, div 4.
31. *Guardianship Act 1987* (NSW) s 45(1).
32. World Medical Association, *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects* (adopted 1964, amended 2013) art 30.
33. Australia, National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research 2007* (updated May 2015) [4.5.6]. See also the new Victorian law: *Medical Treatment Planning and Decisions Act 2016* (Vic) s 72(2) (not yet commenced).
34. *Regulation (EU) No 536/2014 of the European Parliament and of the Council of 16 April 2014 on Clinical Trials on Medicinal Products for Human Use* [2014] OJ L 158/1, art 31(1)(b).
35. *Regulation (EU) No 536/2014 of the European Parliament and of the Council of 16 April 2014 on Clinical Trials on Medicinal Products for Human Use* [2014] OJ L 158/1, art 31(1)(d).

Question 5.5: Preconditions for consent

What preconditions should be met before a decision-maker can consent to participation?

Requirements after consent is obtained

5.27 National guidelines state that even when a substitute decision-maker has consented, a researcher should still explain to the patient what the research is and what their participation will involve, to the extent this is possible.[37]

Question 5.6: Requirements after consent

What should researchers be required to do after consent is obtained?

Waiver of consent requirements

5.28 The Tribunal cannot waive individual consent requirements for clinical trials.[38] NSW Health submits that this is at odds with national guidelines and can create unnecessary delays in situations where an individual needs urgent treatment.[39]

5.29 The national guidelines provide that a review body can waive consent requirements if certain conditions are met, for example, the trial is low risk, it is impractical to gain consent, and there is no known or likely reason the participant would not have consented if asked.[40]

Question 5.7: Waiver of clinical trial consent requirements

Are there any circumstances in which the individual consent requirements for clinical trials should be waived?

Question 5.8: Other issues

Do you have any other comments about the consent requirements for clinical trials?

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36. *Regulation (EU) No 536/2014 of the European Parliament and of the Council of 16 April 2014 on Clinical Trials on Medicinal Products for Human Use* [2014] OJ L 158/1, art 31(1)(e); *Adults with Incapacity (Scotland) Act 2000* s 51(1)(a).
37. Australia, National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research* (2007) (updated May 2015) [4.5.9].
38. *Guardianship Act 1987* (NSW) s 45AB.
39. NSW Health, *Preliminary Submission PGA40*, 8.
40. Australia, National Health and Medical Research Council, *National Statement on Ethical Conduct in Human Research* (2007) (updated May 2015) [2.3.9]–[2.3.10].

6. The relationship between the *Guardianship Act* and mental health legislation

In brief

In this Chapter, we seek your views on whether the relationship between NSW guardianship laws and mental health laws should be changed or clarified.

Relationship between the *Guardianship Act* and the *Mental Health Act* 39
Admission and discharge from mental health facilities 39
Types of treatment 40
Relationship between the *Guardianship Act* and the *Forensic Provisions Act* 41
Should mental health law always prevail? 41

6.1 Guardianship and mental health law often overlap because a person with a mental illness can be the subject of a guardianship order. In these situations, two substitute decision-making regimes will apply, which can lead to potential conflict.

6.2 Two sections of the *Guardianship Act 1987* (NSW) ("*Guardianship Act*") aim to resolve this:

- section 3C, which says that orders or decisions made under the *Mental Health Act 2007* (NSW) ("*Mental Health Act*") take precedence over guardianship orders and enduring guardian instruments, and
- section 34(2), which says that if there is an inconsistency between the provisions of Part 5 of the *Guardianship Act* and the provisions of the *Mental Health Act* or *Mental Health (Forensic Provisions) Act 1990* (NSW) ("*Forensic Provisions Act*"), the provisions of the *Mental Health Act* or *Forensic Provisions Act* prevail.

6.3 Some submissions suggest that because of the way these sections are drafted there is still sometimes confusion about which laws apply. Some stakeholders say guardianship law should prevail over mental health law in certain situations. In this Chapter, we seek your views about these issues.

Relationship between the *Guardianship Act* and the *Mental Health Act*

Admission and discharge from mental health facilities

6.4 Stakeholders have submitted that it is unclear whether guardianship laws or mental health laws determine who can consent to the discharge from mental health facilities of voluntary patients who are under guardianship.[1]

1. Legal Aid NSW, *Preliminary Submission PGA13*, 3–4, Mental Health Review Tribunal, *Preliminary Submission PGA21*, 5–6.

6.5 While a guardian may ask for a person under guardianship to be admitted to a mental health facility, the *Mental Health Act* allows a patient to discharge themselves.[2] Despite this, there has been at least one case where the Public Guardian has argued that a guardian can override a patient's decision to discharge themselves.[3] The confusion has arisen from the fact that a guardian will often have the power to make decisions about accommodation and medical treatment, and to enforce those decisions.[4] The Mental Health Review Tribunal submits that the *Guardianship Act* should prohibit a guardian from making decisions about a patient's discharge from a mental health facility and from re-admitting a patient who has discharged themselves.[5]

Types of treatment

6.6 The Mental Health Commission of NSW submits that the definitions of treatments and procedures under the *Mental Health Act* differ from those under the *Guardianship Act*. Even where the procedures or treatments covered by the respective pieces of legislation overlap, there are different hierarchies of decision-makers:

> These inconsistencies cause real confusion for clinicians providing medical treatment to people who are patients under the Mental Health Act, or who transition either under or out of the Mental Health Act during a course of treatment, and ultimately can result in delays to treatment.[6]

6.7 The Mental Health Coordinating Council submits that there needs to be a clear statement about mental health related treatments that a guardian cannot consent to, for example electroconvulsive therapy.[7] The Mental Health Review Tribunal submits that it should be the decision-maker for all medical decisions in circumstances where a person is detained in a mental health facility.[8]

Question 6.1: Relationship between the *Guardianship Act* and the *Mental Health Act*

(1) Is there a clear relationship between the *Guardianship Act 1987* (NSW) and the *Mental Health Act 2007* (NSW)?

(2) What areas, if any, are unclear or inconsistent?

(3) How could any lack of clarity or inconsistency be resolved?

2. *Mental Health Act 2007* (NSW) s 7, s 8(2)–(3).
3. *White v The Local Health Authority* [2015] NSWSC 417 [67].
4. *Guardianship Act 1987* (NSW) s 21(1)(a), s 21A.
5. Mental Health Review Tribunal, *Preliminary Submission PGA21*, 6.
6. Mental Health Commission of NSW, *Preliminary Submission PGA39*, 3.
7. Mental Health Coordinating Council, *Preliminary Submission PGA08*, 3.
8. Mental Health Review Tribunal, *Preliminary Submission PGA21*, 4.

Relationship between the *Guardianship Act* and the *Forensic Provisions Act*

6.8 The *Forensic Provisions Act* sets out how the criminal law applies to offenders with mental health impairments. It deals with the care, treatment, control and release of forensic patients and patients transferred from correctional centres, and also deals with the functions of the Mental Health Review Tribunal.

6.9 It is clear from the *Guardianship Act* that, in the event of an inconsistency between the medical and dental treatment provisions (Part 5) of the Act and the *Forensic Provisions Act*, the *Forensic Provisions Act* prevails.[9] However, the *Guardianship Act* gives no guidance about how the *Forensic Provisions Act* interacts with any other part of the *Guardianship Act*. What is unclear is what should happen when the two systems come into potential conflict.

6.10 The NSW Civil and Administrative Tribunal ("Tribunal") decides on a case-by-case basis whether to make a guardianship order for a person who is also a forensic patient. For example, if detailed conditions have been imposed under the *Forensic Provisions Act* in relation to accommodation, it could limit the decision-making of a guardian in this area. In such a case, the Tribunal has said it would need to consider carefully the usefulness of a guardianship order.[10]

6.11 The Tribunal has also questioned whether a guardianship order made primarily to ensure a forensic patient complies with conditions under a *Forensic Provisions Act* conditional release order would be consistent with the general principles set out in s 4 of the *Guardianship Act*. While some might argue that appointing a guardian could be in a person's best interests if it helped them to comply with the order and remain living successfully in the community, in the Tribunal's view a guardianship order is "not the appropriate vehicle to achieve this outcome".[11]

Question 6.2: Relationship between the *Guardianship Act* and the *Forensic Provisions Act*

(1) Is there a clear relationship between the *Guardianship Act* and the *Forensic Provisions Act*?

(2) What areas, if any, are unclear or inconsistent?

(3) How could any lack of clarity or inconsistency be resolved?

Should mental health law always prevail?

6.12 Many of the differences between the guardianship and mental health laws are the result of different objectives. As the Mental Health Review Tribunal explains in its preliminary submission:

> There is a fundamental tension between the objectives of the guardianship provisions and the mental health provisions in that the former focuses on the best interests and welfare of the subject person whereas under the mental

9. *Guardianship Act 1987* (NSW) s 34(2).
10. *ERC* [2015] NSWCATGD 14 [54]–[55].
11. *ERC* [2015] NSWCATGD 14 [68]–[69].

> health provisions there is a need to balance the interests of the subject person with the need to protect the safety of the person and the general community.[12]

6.13 The focus on safety in mental health law is one of the reasons why mentally ill people can be detained and treated against their will.

6.14 However, in some areas, the reason for the difference between guardianship and mental health law is unclear. The different laws relating to the termination of a pregnancy are an example.

6.15 Under mental health law, the Mental Health Review Tribunal can approve a termination if the patient cannot consent, or refuses to give consent, and the tribunal considers it is "desirable, having regard to the interests of the patient, to perform the surgical operation".[13] In contrast, under guardianship law the Tribunal can only consent to the termination of a pregnancy if it is "necessary to save the patient's life or to prevent serious damage to the patient's health".[14] It is arguable that this is the more appropriate test.

6.16 The NSW Legislative Council's Standing Committee on Social Issues noted these differences in 2010 and recommended the government consider the need for changes to the *Mental Health Act* and the *Guardianship Act*.[15]

6.17 The Mental Health Review Tribunal notes that under the *Mental Health Act* the Secretary of the Ministry of Health must give consent for the termination of a pregnancy for involuntary patients. It submits that the *Guardianship Act* definition should be adopted instead so that only the Mental Health Review Tribunal can make such decisions, following a hearing.[16]

Question 6.3: Whether mental health laws should always prevail

(1) Is it appropriate that mental health laws prevail over guardianship laws in every situation?

(2) If not, in which areas should this priority be changed?

12. Mental Health Review Tribunal, *Preliminary Submission PGA21*, 5.
13. *Mental Health Act 2007* (NSW) s 101(3); NSW, Legislative Council Standing Committee on Social Issues, *Substitute Decision-Making for People Lacking Capacity*, Report 43 (2010) [12.13].
14. *Guardianship Act 1987* (NSW) s 45(2).
15. NSW Legislative Council Standing Committee on Social Issues, *Substitute Decision-Making for People Lacking Capacity,* Report 43 (2010) rec 34.
16. Mental Health Review Tribunal, *Preliminary Submission PGA21*, 4–5.

7. Restrictive practices

In brief

We look at the current law, policies and practices that guide the use of restrictive practices, and the proposed National Disability Insurance Scheme framework. We ask whether guardianship law in NSW should explicitly address the use of restrictive practices in relation to people with decision-making incapacity.

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7.1 Our terms of reference require us to consider whether guardianship law in NSW should explicitly address the use of restrictive practices for people with decision-making incapacity.

7.2 In this Chapter, we look at the current laws, policies and practices that guide the use of restrictive practices. We consider the National Disability Insurance Scheme ("NDIS") Quality and Safeguarding Framework, which will replace some of the state-based oversight mechanisms that apply to the use of restrictive practices. We seek your views about possible options for reform.

What are restrictive practices?

7.3 The law in NSW does not define restrictive practices. Generally, a restrictive practice is any practice or intervention that restricts the rights or freedom of movement of a person with disability. Restrictive practices are used to manage challenging behaviour or avoid injury, with the primary purpose of protecting the person or others from harm.

7.4 Examples of restrictive practices include physically restraining someone, limiting their freedom of movement or access to objects, or using medication to control their behaviour.[1]

7.5 In the past, restrictive practices were often used as a "first line of response" to difficult behaviour. It is now recognised that restrictive practices can seriously infringe a person's human rights. There is also evidence that using restrictive practices routinely to control behaviour can be harmful to the person and exacerbate the behaviours they intend to control.[2]

7.6 Without consent, many restrictive practices also constitute an assault or wrongful imprisonment. It is important that they be used only when necessary. Some stakeholders have called for reforms that move towards the elimination of restrictive practices altogether.[3]

The regulation of restrictive practices in NSW

Consent under the *Guardianship Act*

7.7 Under the *Guardianship Act 1987* (NSW) ("*Guardianship Act*") a guardian can consent to the use of restrictive practices if:

- the document of appointment specifically empowers an enduring guardian to make such decisions,[4] or
- the Tribunal makes an order granting the guardian a restrictive practices function.[5]

7.8 Before granting a restrictive practices function, the NSW Civil and Administrative Tribunal ("Tribunal") must usually be satisfied that the practice is for the purpose of managing the person's challenging behaviour, and:

- there is some doubt about whether the practice is lawful without informed consent, or
- a guardian is otherwise needed to protect the person.[6]

7.9 Other factors the Tribunal will consider before it grants a restrictive practices function to a guardian include:

- the views of the person under guardianship

1. NSW Civil and Administrative Tribunal Guardianship Division, *Restrictive practices and guardianship,* Fact Sheet (2016) 1.
2. Australian Government Department of Social Services, *NDIS Quality and Safeguarding Framework* (2016) 67.
3. See, eg, Jan Barham MLC, *Preliminary Submission PGA27*, 2; People with Disability Australia, *Preliminary Submission PGA23*, 6.
4. *Guardianship Act 1987* (NSW) s 6E(1)(e).
5. NSW Civil and Administrative Tribunal Guardianship Division, *Fact Sheet: Restrictive practices and guardianship* (2016) 1–2.
6. NSW Civil and Administrative Tribunal Guardianship Division, *Restrictive practices and guardianship,* Fact Sheet (2016) 1–2.

- whether the restrictive practice would address the challenging behaviour
- whether there are less restrictive alternatives, and
- whether there are review and monitoring mechanisms in place.[7]

7.10 A guardian can only consent to using restrictive practices if it is in the person's best interests. The Tribunal usually imposes a condition that the guardian can only consent to a restrictive practice if other, less restrictive, methods are also being used to address the challenging behaviour.[8]

7.11 In 2015–2016, the Tribunal made 135 restrictive practices orders.[9]

The use of restrictive practices in government facilities

7.12 In the absence of specific laws, NSW government policies control the use of restrictive practices in government-run and government-funded facilities.

7.13 All facilities run or funded by the NSW Department of Family and Community Services ("FACS") apply FACS's behavioural support policy. The policy requires authorisation from an appropriate person or body (for example, a specialist panel that includes clinical experts) and informed legal consent (for example, from a guardian with a restrictive practices function). The policy also includes a list of prohibited practices.[10] Similar policy documents govern the use of restrictive practices in public mental health facilities and aged care facilities.[11]

7.14 The Commonwealth and state and territory governments have committed to a national framework for reducing or eliminating the use of restrictive practices in the disability service sector. The national framework, which is said to be consistent with the UN *Convention*, sets out six core strategies to be implemented by 2018. These include:

- placing the perspectives of people with disability at the centre of behaviour control measures
- changing the culture of organisations who work with people with disability, and
- developing the skills of disability workers to better equip them to use alternative measures for controlling behaviour.[12]

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7. NSW Civil and Administrative Tribunal Guardianship Division, *Restrictive practices and guardianship,* Fact Sheet (2016) 2–3.
8. NSW Civil and Administrative Tribunal Guardianship Division, *Restrictive practices and guardianship,* Fact Sheet (2016) 3.
9. Information provided by the Tribunal on 16 February 2017.
10. Department of Family and Community Services NSW, Office of the Senior Practitioner Ageing, Disability and Home Care, *Behaviour Support Policy* (2009, revised 2012) 23.
11. NSW Health Mental Health and Drug and Alcohol Office, *Aggression, Seclusion and Restraint in Mental Health Facilities in NSW*, Policy Directive 2012_035 (2012, revised 2016); NSW Health, Mental Health and Drug and Alcohol Office, *Aged Care – Working with People with Challenging Behaviours in Residential Aged Care Facilities*, Guideline 2006_014 (2006, revised 2014).
12. Australian Government, Department of Social Services, *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* (2014).

The NDIS Quality and Safeguarding Framework

7.15 The NDIS, which is being rolled out in NSW, fundamentally changes the way disability support is funded and delivered. Previously, the NSW Government provided most disability services in NSW. However, under the NDIS, the system will be replaced with a Commonwealth administered system that includes the market-based supply of supports. The NSW Government is currently transferring services to the non-government sector. All services will be transferred by 30 June 2018[13] and FACS policies regulating the use of restrictive practices in the disability sector will no longer apply.

7.16 The NDIS Quality and Safeguarding Framework underpins the NDIS. The Framework will be supported by legislation that:

- defines restrictive practices
- prohibits particular practices
- sets out the circumstances in which a provider can use a restrictive practice and the conditions that must be met before it can be used
- establishes a senior practitioner to respond to incidents, make directions and recommendations and examine current practice
- sets competency standards for practitioners around the use of behaviour supports, and
- establishes reporting requirements.[14]

7.17 While the legislation will set out the key principles around the use of restrictive practices, state and territory legislation will continue to play a role. In particular, existing state-based consent and authorisation mechanisms (such as the *Guardianship Act*) will continue to apply.[15]

Problems with the regulation of restrictive practices

7.18 Stakeholders and academics have raised concerns about the way restrictive practices are regulated in NSW. Commonwealth legislation and other oversight mechanisms may resolve some of these problems. However, since the regulatory landscape is in flux, it is difficult to know what will be resolved and what additional problems may emerge.

7.19 Issues of particular concern include:

- **The use of restrictive practices may breach international law.** Article 15 of the UN *Convention on the Rights of Persons with Disabilities* ("the UN *Convention*") stipulates that people with disability have a right to be free from torture and cruel, inhuman or degrading treatment or punishment. The UN

13. NSW Government, "Transfer of New South Wales disability services" *National Disability Insurance Scheme* < http://ndis.nsw.gov.au/about-ndis-nsw/transfer-of-nsw-disability-services/>.
14. Australian Government Department of Social Services, *NDIS Quality and Safeguarding Framework* (2016) 71–72.
15. Australian Government Department of Social Services, *NDIS Quality and Safeguarding Framework* (2016) 17.

Committee on the Rights of Persons with Disabilities has urged Australia to end the use of restrictive practices to bring it into line with Article 15.[16] A goal of the NDIS Quality and Safeguarding Framework is to reduce or eliminate the use of restrictive practices. The Framework envisages moving towards a system in which using restrictive practices to respond to concerning behaviour is the exception and underpinned by positive behaviour support.[17]

- **There is no consistent definition of a restrictive practice.** For example, the Tribunal does not necessarily consider the use of medication to control behaviour to be a restrictive practice. This conflicts, in some cases, with the approach taken by FACS and the Public Guardian.[18] This can lead to uncertainty about what rules apply or what consent needs to be given in a particular case. A Commonwealth legislative definition of restrictive practices might resolve this issue.

- **There is no consistent approach to regulation.** Different government agencies regulate the use of restrictive practices through inconsistent policies. Even when the Commonwealth passes NDIS-related legislation, this legislation will sit in contrast to the regulation of restrictive practices in the mental health and aged care sectors.

- **There is minimal regulation of restrictive practices in informal settings.** Sometimes family members care for people with disability at home without any formal guardianship arrangements in place. Even with Commonwealth legislation in place, it is likely the regulation of restrictive practices in this context would be limited to criminal law sanctions, for example, for assault or false imprisonment.

- **Consent and authorisation requirements are inadequate.** Some submissions have raised concerns about the consent and authorisation requirements used in government-funded facilities.[19] When the NDIS is rolled these policies will no longer apply.

- **There is no independent body to monitor the use of restrictive practices.** The NSW Ombudsman has some oversight over FACS run or funded facilities but its power is limited.[20] The senior practitioner role in the NDIS framework will include overseeing behaviour support practitioners and providers, and providing clinical governance and leadership to clinicians.[21]

16. United Nations, Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Australia*, 10th sess, 118th mtg, UN Doc CRPD/C/AUS/CO/1 (21 October 2013) 5 [36].
17. Australian Government Department of Social Services, *NDIS Quality and Safeguarding Framework* (2016) 68.
18. See, eg, Department of Family and Community Services NSW, Office of the Senior Practitioner Ageing, Disability and Home Care, *Behaviour Support Policy* (2009, revised 2012) 17; Office of the Public Guardian NSW, *Determining whether to consent to the use of restraint on an elderly person in a care facility*, Position Statement 11 (2007) 2–3, NSW Civil and Administrative Tribunal, Guardianship Division, *Restrictive practices and guardianship,* Fact Sheet (2016) 3.
19. See, eg, Intellectual Disability Rights Service, *Preliminary Submission PGA44*, 9.
20. *Community Services (Complaints, Reviews and Monitoring) Act 1993* (NSW) s 27(b).
21. Australian Government Department of Social Services, *NDIS Quality and Safeguarding Framework* (2016) 73– 74.

Question 7.1: Problems with the regulation of restrictive practices

What are the problems with the regulation of restrictive practices in NSW and what problems are likely to arise in future regulation?

Should NSW law address the use of restrictive practices?

7.20 In 2010, the NSW Legislative Council Standing Committee on Social Issues recommended that the NSW Government consider legislation on the use of restrictive practices in the context of guardianship.[22] Many stakeholders also support legislation expressly dealing with the use of restrictive practices.[23]

7.21 In 2014, the NSW Government released a consultation draft of the Disability Inclusion Bill 2014 (NSW) which dealt with restrictive practices.[24] However, the relevant provisions were ultimately removed because the Government decided to wait for Commonwealth regulation of the area under the NDIS.[25]

7.22 The NDIS Quality and Safeguarding Framework now gives a clearer idea of what the Commonwealth regulation of the NDIS will look like, but not the full picture.

7.23 Since the form of regulation is still unclear, it may still be necessary to wait for Commonwealth action before enacting complementary laws in NSW. However, we think it is still useful to discuss what the key elements of any future legislation should be. The *Guardianship Act* may not be the appropriate vehicle for regulating restrictive practices since the use of restrictive practices extends beyond guardianship.

7.24 We do know a number of things about the NDIS framework:

- the states and territories will remain responsible for consent and authorisation mechanisms
- the framework is unlikely to regulate private arrangements in the home, and
- the framework will not cover other spheres such as aged care and mental health.

7.25 Given the clinical context, there are good reasons to distinguish regulating restrictive practices in mental health facilities and regulating restrictive practices in the aged care and disability sectors. The aged care sector, because of the funding arrangements, is arguably a Commonwealth responsibility. The Australian Law

22. NSW, Legislative Council Standing Committee on Social Issues, *Substitute Decision-Making for People Lacking Capacity* (2010) [10.14] – [10.17], rec 27.
23. See, eg, Alzheimer's Australia NSW, *Preliminary Submission PGA14*, 6–7; Disability Council NSW, *Preliminary Submission PGA26*, 17; Bernhard Ripperger and Laura Joseph, *Preliminary Submission PGA31*, 11–12; NSW Ombudsman Office, *Preliminary Submission PGA41*, 7–8; Nell Brown, *Preliminary Submission PGA42*, 6; Intellectual Disability Rights Service, *Preliminary Submission PGA44*, 9; Confidential, *Preliminary Submission PGA48*, 1; NSW Trustee & Guardian, *Preliminary Submission PGA50*, 11.
24. Disability Inclusion Bill 2014 (NSW) (Public Consultation Draft) cl 37–41.
25. NSW, *Parliamentary Debates*, Legislative Council, 23 October 2014, 1787–1788.

Reform Commission ("ALRC") recently proposed amendments to the *Aged Care Act 1997* (Cth) to regulate the use of restrictive practices in aged care facilities.[26]

7.26 Legislation may not be the best way to deal with some of the problems associated with the use of restrictive practices. The need for restrictive practices can be reduced by:

- reforming policy and procedure
- educating service providers, family and carers, and
- addressing the environmental factors that may trigger challenging behaviours.

We anticipate that the Commonwealth's senior practitioner and behaviour support plan specialists will support these improvements in the disability sphere.

Question 7.2: Restrictive practices regulation in NSW

(1) Should NSW pass legislation that explicitly deals with the use of restrictive practices?

(2) If so, should that legislation sit within the *Guardianship Act* or somewhere else?

(3) What other forms of regulation or control could be used to deal with the use of restrictive practices?

Possible elements of a law that regulate the use of restrictive practices

Who should any regulation apply to?

7.27 In NSW, only government and government-funded providers are bound to apply policies that regulate restrictive practices.[27] Private service providers and home-based carers are not so regulated and arguably unprotected. This means that people who may have the same needs are not provided with the same safeguards. In 2010, the Queensland Law Reform Commission criticised a similar system in Queensland for arbitrarily distinguishing between the two groups.[28]

7.28 NSW legislation could apply to people who fall outside the NDIS regime: for example, aged care providers (if the Commonwealth does not fully cover this sector) and individuals providing informal care for a family member.

26. Australian Law Reform Commission, *Elder Abuse*, Discussion Paper 83 (2016) proposal 11-7.
27. Department of Family and Community Services NSW, Office of the Senior Practitioner Ageing, Disability and Home Care, *Behaviour Support Policy* (2009, revised 2012) 1; NSW Health, Mental Health and Drug and Alcohol Office, *Aged Care – Working with People with Challenging Behaviours in Residential Aged Care Facilities*, Guideline 2006_014 (2006, revised 2014), 29.
28. Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws*, Report No 67 (2010) [19.136].

Question 7.3: Who should be regulated?

Who should any NSW regulation of the use of restrictive practices apply to?

How should restrictive practices be defined?

7.29 The National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector has a definition of restrictive practices, which is presented in the NDIS Quality and Safeguarding Framework as follows:

> **Seclusion**: the sole confinement of a person with disability in a room or physical space at any hour of the day or night where voluntary exit is prevented, impeded or not facilitated.
>
> **Chemical restraint:** the use of medication or chemical substance for the primary purpose of influencing a person's behaviour or movement. It does not include the use of medication prescribed by a medical practitioner for the treatment of, or to enable treatment of, a diagnosed mental disorder, a physical illness or physical condition.
>
> **Mechanical restraint:** the use of a device to prevent, restrict or subdue a person's movement for the primary purpose of influencing their behaviour. It does not include the use of devices for therapeutic or non-behavioural purposes. For example, it may include the use of a device to assist a person with functional activities as part of occupational therapy or to allow for safe transportation.
>
> **Physical restraint:** the sustained or prolonged use or action of physical force to prevent, restrict or subdue movement of a person's body, or a part of their body, for the primary purpose of influencing the person's behaviour. Physical restraint is distinct from the use of a hands technique in a reflexive way to guide or redirect a person away from potential harm/injury, consistent with what could reasonably be considered the exercise of care towards a person.
>
> **Psycho-social restraints**: usually involves the use of 'power-control' strategies.
>
> **Environmental restraints**: restricts a person's free access to all parts of their environment.
>
> **Consequence driven practices**: usually involve withdrawing activities or items.[29]

7.30 We expect this definition will form the basis of the Commonwealth's anticipated legislation. There is a strong argument that, if NSW were to regulate, it should use a consistent definition.

7.31 Other states and territories include within their definitions physical restraints, mechanical restraints, chemical restraints and seclusion.[30] Tasmania also includes

29. Australian Government Department of Social Services, NDIS Quality and Safeguarding Framework (2016) 67 citing Australian Government Department of Social Services, National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service (2014) 4–5.
30. See, eg, *Disability Services Act 2006* (Qld) s 144–147.

environmental restriction.[31] Some states include within their definition restricting access to certain objects in order to control behaviour.[32]

7.32 The Canadian province of British Columbia defines restraint to include electronic means of restraint.[33]

Question 7.4: Defining restrictive practices

How should restrictive practices be defined?

When should restrictive practices be permitted?

7.33 Some stakeholders agree with the UN Committee that Australia should work towards eliminating restrictive practices.[34] However, if, as the NDIS Quality and Safeguarding Framework contemplates, there is still some need for restrictive practices, it will fall to the law to set out the circumstances in which they can be used.

7.34 In its recent discussion paper on elder abuse the ALRC proposed that restrictive practices should only be used in residential aged care to prevent physical harm.[35] The NSW Trustee and Guardian submits restrictive practices should only be used in exceptional circumstances, on a short-term basis, and when necessary to protect the person's safety and interests.[36]

Question 7.5: When restrictive practices should be permitted

In what circumstances, if any, should restrictive practices be permitted?

Consent and authorisation

7.35 We summarised the NSW consent mechanisms that apply to the use of restrictive practices at [7.7]–[7.10]. We now ask you to consider whether any aspect of these mechanisms needs to change.

Should private guardians be able to consent to the use of restrictive practices?

7.36 Some say it is inappropriate for private guardians (as opposed to the Public Guardian) to consent to the use of restrictive practices.[37] Arguments against private guardians being able to give consent include:

- The relationship between a guardian and a person is a "fiduciary relationship", meaning the guardian must act only in the person's interests. For example,

31. *Disability Services Act 2011* (Tas) s 34.
32. *Disability Services Act 2006* (Qld) s 144, definition of "restricting access"; *Disability Services Act* (NT) s 35.
33. *Community Care and Assisted Living Act Residential Care Regulation 2009* (BC) cl 1, definition of "restraint".
34. See, eg, Jan Barham MLC, *Preliminary Submission PGA27*, 2.
35. Australian Law Reform Commission, *Elder Abuse*, Discussion Paper 83 (2016) proposal 11-7.
36. *NSW Trustee and Guardian*, *Preliminary Submission PGA50*, 10.
37. Australian Centre for Health Law Research, *Preliminary Submission PGA48*, 6.

where restrictive practices are used to protect service provider staff from harm instead of the person themselves, consenting to the use of restrictive practices would be in breach of a guardian's fiduciary duty.

- Any decision to give consent should be made in a principled, transparent and systematic way. For private individuals, this requirement is difficult to meet.[38]

- Guardians do not have the required clinical training and understanding to grasp fully the gravity of the consequences of using restrictive practices on a person.[39]

7.37 Some states do not allow guardians to consent to the use of restrictive practices. In Victoria, for example, a service provider must apply to the Secretary of the Department of Health and Human Services to authorise the use of restrictive practices.[40] In Tasmania, either the Secretary of the Department of Health and Human Services or the Guardianship and Administration Board can grant authorisation.[41]

7.38 In South Australia, a guardian or the substitute decision-maker appointed under an advance care directive can consent to the use of restrictive practices. However, a service provider must apply to the tribunal to use detention or seclusion.[42]

Factors a decision-maker must consider before authorising the use of restrictive practices

7.39 We set out some of the factors the Tribunal considers before granting a restrictive practices function to a guardian at [7.8]–[7.9].

7.40 We expect that Commonwealth NDIS legislation will set out key principles around the use of restrictive practices, including that:

- the restrictive practice is the least restrictive response available

- the restrictive practice is only used as a last resort, and

- the risk of harm posed by the restrictive practice is proportionate to the risk of harm posed by the challenging behaviour.[43]

7.41 Factors that tribunals and statutory bodies in other states and territories must consider before authorising the use of restrictive practices include:

- whether it is in the person's best interest[44]

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38. Confidential, *Preliminary Submission PGA48*, 7.
39. Michael Williams, John Chesterman and Richard Laufer, "Consent versus scrutiny: Restricting liberties in post-Bournewood Victoria" (2014) 21 *Journal of Law and Medicine* 641, 655–656.
40. *Disability Act 2006* (Vic) s 135(1).
41. *Disability Services Act 2011* (Tas) s 38, s 42.
42. Office of the Public Advocate, South Australia *Guardian Consent for Restrictive Practices in Disability Settings*, Draft Policy Document, (2014) 7; Office of the Public Advocate, South Australia , *Guardian Consent for Restrictive Practices in Residential Aged Care Settings*, Draft Policy Document ((2016) 6; *Guardianship and Administration Act 1993* (SA) s 32(1)(b), (c).
43. Australian Government Department of Social Services, *NDIS Quality and Safeguarding Framework* (2016), 73.
44. See, eg, *Disability Services Act 2011* (Tas) s 38(5)(a), s 43(2)(a).

- whether the person's behaviour has caused or will cause serious harm to themselves, others, or serious property damage where this involves the risk of harm to themselves or others[45]
- whether the restrictive practice will benefit the person[46]
- whether it is the least restrictive option or the last resort[47]
- in the case of seclusion, whether the person will be supplied with the necessary comforts such as adequate bedding, food, and toilet access[48]
- whether there is a behaviour support plan and whether the proposed restrictive practice is included in it[49]
- the nature and degree of any significant risk associated with the restrictive practice,[50] and
- whether the person will be safeguarded from abuse, exploitation and neglect.[51]

Urgency

7.42 It is the Tribunal's practice in urgent situations to make a "short order" without a hearing authorising the use of restrictive practices. The Tribunal conducts a review hearing later.[52] Whether a situation is urgent will depend on the facts of the case. Generally, the Tribunal requires a real, material and immediate risk to the health and/or safety of the person. A short order is always of short duration, generally only for a few weeks.

7.43 In the Northern Territory, restrictive practices can be used without the normal authorisation requirements if the disability service provider believes it is necessary because there is an imminent risk of the person causing serious physical harm to themselves or others.[53] The restraint must be the least restrictive possible, and notice must immediately be given to the CEO of the residential facility in an approved form.[54] Victoria has similar requirements.[55]

7.44 Queensland's legislation only captures emergency situations where approval has been sought but not yet given,[56] or where the consent period for restrictive practices very recently ended.[57]

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45. See, eg, *Disability Act 2006* (Vic) s 140(a).
46. See, eg, *Disability Act 2006* (Vic) s 141(2)(b).
47. See, eg, *Disability Services Act 2006* (Qld) s 143(2)(c)(ii).
48. See, eg, *Disability Services Act 2006* (Vic) s 140(d).
49. See, eg, *Disability Services Act 2006* (Qld) s 43.
50. See, eg, *Disability Services Act 2011* (Tas) s 43(2)(e), s 38(5)(e).
51. See, eg, *Disability Services Act 2006* (Qld) s 150(2)(c)(iv)(B).
52. NSW Civil and Administrative Tribunal Guardianship Division, *Restrictive practices and guardianship,* Fact Sheet (2016) 2.
53. *Disability Services Act* (NT) s 42.
54. *Disability Services Act* (NT) s 42(2).
55. *Disability Act 2006* (Vic) s 147.
56. *Disability Services Act 2006* (Qld) s 154, s 171.
57. *Disability Services Act 2006* (Qld) s 169.

Question 7.6: Consent and authorisation mechanisms

(1) Who should be able to consent to the use of restrictive practices?

(2) What factors should a decision-maker have to consider before authorising a restrictive practice?

(3) What should be the mechanism for authorising restrictive practices in urgent situations?

(4) What changes, if any, should be made to NSW's consent and authorisation mechanisms for the use of restrictive practices?

Safeguards: reviews and monitoring

7.45 Some submissions have called for increased safeguards, including monitoring the use of restrictive practices and mandatory reporting.[58]

7.46 The NDIS Quality and Safeguarding Framework mandates transparency and accountability by requiring NDIS providers to report on the use of restrictive practices. The framework further provides for the monitoring and review of this data by the provider, the relevant positive behaviour support practitioner, and the NDIS senior practitioner.[59]

7.47 In Victoria, there are strict mandatory reporting requirements for service providers, and authorised program officers are required to send reports to the senior practitioner every 12 months.[60] In both Victoria and Tasmania the senior practitioner must monitor the use of restrictive practices.[61] Similarly in Queensland, service providers must inform the Chief Executive about the use of restrictive practices.[62] In the Northern Territory, legislation requires that service providers keep a record of every use of a restrictive practice.[63]

7.48 The independence of the monitoring person or body is arguably a key factor of a useful oversight mechanism. In Victoria, an "independent person" (they cannot have any affiliation with a disability service provider) must be made available to explain a change to a person's behaviour support plan if the change involves the use of a more restrictive form of restraint or seclusion.[64]

7.49 One stakeholder submits that a state register should keep records that outline the restrictive practice, the reasons for the practice, the age of the person subject to the practice, and the facility that is administering the practice.[65]

58. See, eg, NSW Council for Intellectual Disability, *Preliminary Submission PGA18*, 6, 11; National Disability Services, *Preliminary Submission PGA24*, 6; NSW Ombudsman Office, *Preliminary Submission PGA41*, 8–9.
59. Australian Government Department of Social Services, *NDIS Quality and Safeguarding Framework* (2016), 72.
60. *Disability Act 2006* (Vic) s 148, s 139.
61. *Disability Act 2006* (Vic) s 148(1)(a); *Disability Services Act 2011* (Tas) s 35(f).
62. *Disability Services Act 2006* (Qld) s 199.
63. *Disability Services Act* (NT) s 43, s 44.
64. *Disability Act 2006* (Vic) s 143(1A).
65. Nell Brown, *Preliminary Submission PGA42*, 6.

Question 7.7: Safeguards for the use of restrictive practices

What safeguards should be in place to ensure the appropriate use of restrictive practices in NSW?

Use of behaviour support plans

7.50 While NSW has a detailed policy on behaviour support plans, it does not have statutory backing unlike in other states and territories.[66] Clinical evidence suggests high quality support plans result in "less restrictive interventions".[67] Enshrining plans in legislation could encourage their use and improve their quality and consistency.

Question 7.8: Requirements about the use of behaviour support plans

(1) Should the law include specific requirements about the use of behaviour support plans?

(2) If so, what should those requirements be?

66. Department of Family and Community Services NSW, Office of the Senior Practitioner Ageing, Disability and Home Care, *Behaviour Support Policy* (2009, revised 2012) See, eg, *Disability Act 2006* (Vic) s 54, s 141; s 150; *Disability Services Act* (NT) s 36.

67. Claire Spivakovsky, *Restrictive Interventions in Victoria's Disability Sector: Issues for Discussion and Reform*, Discussion Paper, Office of the Public Advocate, Victoria(2012) 9, citing L Webber and others, "Factors Influencing Quality of Behaviour Support Plans and the Impact of Plan Quality on Restrictive Intervention Use" (2011) 1 *International Journal of Positive Behavioural Support* 24.

Appendix A
Preliminary submissions

PGA01 Maxwell Watts and Mareea Watts (15 February 2016)
PGA02 Lise Barry (23 February 2016)
PGA03 Dr John Carter (9 March 2016)
PGA04 Lina Sultana (10 March 2016)
PGA05 NSW Disability Network Forum (18 March 2016)
PGA06 [Confidential] (18 March 2016)
PGA07 Seniors Rights Service (18 March 2016)
PGA08 Mental Health Coordinating Council (18 March 2016)
PGA09 Bridgette Pace (19 March 2016)
PGA10 Council on the Ageing NSW (19 March 2016)
PGA11 Michael Cochran and Hilda Cochran (20 March 2016)
PGA12 Kellie Jefferson (20 March 2016)
PGA13 Legal Aid NSW (21 March 2016)
PGA14 Alzheimer's Australia NSW (21 March 2016)
PGA15 Supreme Court of NSW (21 March 2016)
PGA16 Medical Insurance Group Australia (MIGA) (21 March 2016)
PGA17 Carers NSW (21 March 2016)
PGA18 NSW Council for Intellectual Disability (21 March 2016)
PGA19 NSW Council for Civil Liberties (21 March 2016)
PGA20 Avant Mutual Group Limited (21 March 2016)
PGA21 Mental Health Review Tribunal (21 March 2016)
PGA22 BEING (21 March 2016)
PGA23 People with Disability Australia (21 March 2016)
PGA24 National Disability Services (21 March 2016)
PGA25 Peter Deane (21 March 2016)
PGA26 Disability Council NSW (21 March 2016)
PGA27 Jan Barham (21 March 2016)
PGA28 Department of Rehabilitation Medicine St Vincent's Hospital (21 March 2016)
PGA29 Vanessa Browne (21 March 2016)
PGA30 June Walker (21 March 2016)
PGA31 Bernhard Ripperger and Laura Joseph (28 March 2016)
PGA32 NSW Young Lawyers (29 March 2016)
PGA33 [Confidential] (29 March 2016)
PGA34 John Friedman (30 March 2016)
PGA35 Institute of Legal Executives (31 March 2016)
PGA36 [Confidential] (31 March 2016)
PGA37 Mary Lou Carter (1 April 2016)
PGA38 Our Voice Australia (1 April 2016)
PGA39 NSW Mental Health Commission (1 April 2016)

PGA40 The South Eastern Sydney Local Health District Human Research Ethics Committee (1 April 2016)
PGA41 NSW Ombudsman Office (1 April 2016)
PGA42 Nell Brown (3 April 2016)
PGA43 Law Society of NSW (4 April 2016)
PGA44 Intellectual Disability Rights Service (4 April 2016)
PGA45 Craig Ward (1 April 2016)
PGA46 [Confidential] (30 March 2016)
PGA47 Australian Centre for Health Law Research (4 April 2016)
PGA48 [Confidential] (4 April 2016)
PGA49 NSW Health Commission (4 April 2016)
PGA50 NSW Trustee and Guardian (7 April 2016)
PGA51 Michael Murray (6 April 2016)
PGA52 Australian Lawyers Alliance (8 April 2016)
PGA53 Mental Health Carers Arafmi NSW Inc (18 April 2016)
PGA54 NSW Family and Community Services (27 April 2016)

Appendix B
Submissions

GA1 Mental Health Coordinating Council (24 September 2016)
GA2 Royal Australasian College of Physicians (13 October 2016)
GA3 Justice Health and Forensic Mental Health Network (12 October 2016)
GA4 Seniors Rights Service (14 October 2016)
GA5 Aged and Community Services NSW and ACT (13 October 2016)
GA6 NSW Disability Network Forum (13 October 2016)
GA7 NSW Council for Intellectual Disability (16 October 2016)
GA8 Bridgette Pace (17 October 2016)
GA9 Combined Pensioners and Superannuants Association of NSW Inc (17 October 2016)
GA10 Mental Health Carers NSW (17 October 2016)
GA11 Alzheimer's Australia NSW (17 October 2016)
GA12 Carers NSW (17 October 2016)
GA13 NSW Council of Social Service (17 October 2016)
GA14 Cognitive Decline Partnership Centre (17 October 2016)
GA15 Schizophrenia Fellowship of NSW (17 October 2016)
GA16 Intellectual Disability Rights Service (17 October 2016)
GA17 Physical Disability Council of New South Wales (18 October 2016)
GA18 Legal Aid NSW (18 October 2016)
GA19 NSW Civil and Administration Tribunal - Guardianship Division (18 October 2016)
GA20 People with Disability Australia (22 October 2016)
GA21 Synapse (24 October 2016)
GA22 Stephanie Travers (24 October 2016)
GA23 Capacity Australia (25 October 2016)
GA24 Royal Australian and New Zealand College of Psychiatrists (26 October 2016)
GA25 Mental Health Commission of NSW (27 October 2016)
GA26 Medical Insurance Group Australia (27 October 2016)
GA27 The Law Society of NSW Young Lawyers Civil Litigation Committee (28 October 2016)
GA28 NSW Trustee and Guardian (28 October 2016)
GA29 The Law Society of NSW (8 November 2016)
GA30 Mid North Coast Community Legal Centre (31 October 2016)
GA31 NSW Family and Community Services (9 November 2016)
GA32 Multicultural NSW (29 November 2016)

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