MHCN mental health carers

NSW Law Reform Commission
Level 3, Henry Deane Building
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SYDNEY
NSW 2000 Australia

www.lawreform.justice.nsw.gov.au

5 June 2017

Re: Question Paper 4

Dear Sir/Madam

Mental Health Carers NSW is the peak body in NSW representing the interests of the carers of people with a mental illness. Our vision is for an inclusive community and connected carers; and our mission is to empower carers for mental health. We undertake systemic advocacy on behalf of mental health carers to improve their recognition and support in mental health and related social services.

Thank you for providing the opportunity to us to comment on the review of the Guardianship Act 1987 (NSW) in April 2016 and for this opportunity to comment on Question Paper 4 Safeguards and Procedures. We have noted the format of the questions detailed in this 'question papers' and have structured this paper to respond to the questions raised.

Our overall Observations and Recommendations

A register of guardians

A registration system for guardians and managers holds more benefits than disadvantages. There should be a national system but NSW should introduce one in the interim if necessary. It should be mandatory for all enduring arrangements and orders to be registered. Publicly available details on the existence of an enduring arrangement or order should be minimal such as only the person's name and address, and that an enduring arrangement or order has been registered but not the details of the enduring arrangement or order. There should be limits to access to any further details except by application to the registrar.

Establishment of a Public Advocate for NSW

There should be established in NSW the role of a Public Advocate, which undertakes systematic advocacy and can investigate complaints or allegations concerning a particular adult with impaired decision making capacity. The Public Guardian or a public advocate should be able to assist people

with a disability who are not under guardianship. The role of Public Advocate should be separate from the role of Public Guardian.

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Question Paper number 4:

Questions	*Our Position*
2. Enduring guardianship	
Question 2.2: When enduring guardianship takes effect	
Should the *Guardianship Act 1987* (NSW) contain a procedure that must be followed before an enduring guardianship appointment can come into effect? If so, what should this process be?	The answer to this question is conditional on the introduction of some form of registration process, which is discussed below. If a registration process is in place, enduring guardians should then be required to notify a registrar if they believe the appointor has lost capacity and they intend to start using their powers. The registrar would then note this on the registration system.
Question 2.3: Reviewing an enduring guardian appointment	
Are the powers of the NSW Civil and Administrative Tribunal to review an enduring guardian appointment sufficient? If not, what should change?	There should be greater consistency between the powers the Tribunal has when reviewing a power of attorney and when reviewing an appointment of enduring guardian.
Question 2.4: Ending an enduring arrangement	

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Questions	Our Position
What changes, if any, should be made to the *Guardianship Act 1987* (NSW) concerning: (a) The resignation of an enduring guardian, and (b) The revocation of an enduring guardianship arrangement?	The Guardianship Board or the Civil and Administrative Tribunal should have the power to investigate, revoke, or replace an alternative enduring guardian/attorney.
3. Guardianship orders and financial management orders	
Question 3.2: Time limits for orders	
(1) Are the time limits that apply to guardianship orders appropriate? If not, what should change? (2) Should time limits apply to financial management orders? If so, what should these time limits be?	The time limits that apply to guardianship orders and financial management orders by the Tribunals should be the same 30 days, 1 year, 3 years and 5 years, depending on the circumstances. The same time limits should apply to enduring guardianships and enduring powers of attorney. All orders should be reviewed every year unless there is agreement by all parties for a longer period of review. Reviews should consider fraud and appropriate decisions of the guardian or financial manager.

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Questions	*Our Position*
Question 3.3: Limits to the scope of financial management orders	
Should the *Guardianship Act 1987* (NSW) require the NSW Civil and Administrative Tribunal to consider which parts of a person's estate should be managed?	Financial management orders should specify the extent of the order.
Question 3.4: When orders can be reviewed	
(1) What changes, if any, should be made to the process for reviewing guardianship orders? (2) Should the NSW Civil and Administrative Tribunal be required to review financial management orders regularly? (3) What other changes, if any, should be made to the process for reviewing financial management orders?	All orders (guardianship and financial) should be reviewed every year unless there is an agreement by all parties for a longer period of review.
Question 3.5: Reviewing a guardianship order	
(1) What factors should the NSW Civil and Administrative Tribunal consider when reviewing a guardianship order? (2) Should these factors be set out in the *Guardianship Act 1987* (NSW)?	Any instances of fraud/suspected fraud and apparently inappropriate decisions. Additionally decisions that are not consistent with the consumer's desires and preferences unless they are unsafe. The Act should set out some guidelines without being too prescriptive.

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Questions	Our Position
Question 3.6: Grounds for revoking a financial management order	
(1) Should the *Guardianship Act 1987* (NSW) expressly allow the NSW Civil and Administrative Tribunal to revoke a financial management order if the person no longer needs someone to manage their affairs?	All appointments (Guardians and Financial Managers) can be replaced following a review.
4. A registration system	
Question 4.1: Benefits and disadvantages of a registration system	
(1) What are the potential benefits and disadvantages of a registration system? Do the benefits outweigh the disadvantages? (2) Should NSW introduce a registration system? (3) Should NSW support a national registration system? If NSW was to implement a registration system, what should be the key features of this system?	• A registration system for guardians and managers holds more benefits than disadvantages. • There should be a national system but NSW should introduce one in the interim if necessary. • It should be mandatory for all enduring arrangements and orders to be registered. • Publicly available details on the existence of an enduring arrangement or order should be minimal such as only the person's name and address, and that an enduring arrangement or order has been registered but not the details of the enduring arrangement or order. There should be limits to access to any further details except by application to the registrar.
5. Holding guardians and financial managers to account	

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Questions	Our Position
Question 5.1: A statement of duties and responsibilities	
(1) Should the *Guardianship Act 1987* (NSW) and/or the *NSW Trustee and Guardian Act 2009* (NSW) include a statement of the duties and responsibilities of guardians and financial managers?	• The Act should contain a statement of duties and responsibilities of guardians and financial managers. • Those appointed should sign to say they will adhere to them. • There should be tighter oversight and restrictions on the powers and actions of financial managers. • Both guardians and financial managers should submit regular reports to the registrar or tribunal. Report can be minimal if little activity had taken place and be automated and online for ease of completion.
Question 5.2: The supervision of private managers	
What, if anything, should change about the NSW Trustee and Guardian's supervisory role under the *NSW Trustee and Guardian Act 2009* (NSW)?	Family members or others with an interest in the affairs of the consumer should be able to request a review by the NSW Trustee and Guardian of an order or a review the appointment of an enduring guardian or the power of attorney.
Question 5.3: Reporting requirements for private financial managers	
Should the *NSW Trustee and Guardian Act 2009* (NSW) be amended to allow the NSW Trustee and Guardian to decide how often private managers should lodge accounts?	Yes
Question 5.4: Removing private financial managers from their role	

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Questions	*Our Position*
(1) When should a private financial manager be removed from their role? (2) Should the *Guardianship Act 1987* (NSW) set out the circumstances in which a private financial manager can or must be removed from their role more clearly?	In addition to the obvious circumstances of incompetence, fraud and inappropriate decision making, a private financial manager should be able to be removed when it is clear that their decisions are unduly conservative and cautious, lacking in timeliness or are inconsistent with the consumer's desires and preferences expect where decisions on this basis may be unsafe.
Question 5.5: Reporting requirements of private guardians	
Should private guardians be required to submit regular reports on their activities? If so, to whom should they be required to report?	A yearly report can be minimal if little activity had taken place, be automated and online for ease of completion. Where there has been more activity by the guardian then a longer report may be necessary but could also be online and automated for speed and convenience.
Question 5.6: Directions to guardians	
Who should be able to apply to the NSW Civil and Administrative Tribunal for directions on the exercise of a guardian's functions?	We see advantages in allowing interested persons to apply to the NSW Civil and Administrative Tribunal for a decision giving direction to the appointed or enduring guardian.
Question 5.7: Removing private guardians from their role	
(1) When should a private guardian be removed from their role?	In addition to the obvious circumstances of incompetence, fraud and inappropriate decision making a private guardian should be able to be removed when it is clear that their decisions are unduly conservative and cautious, lacking in timeliness or are

Questions	Our Position
(2) Should the *Guardianship Act 1987* (NSW) set out these circumstances?	inconsistent with the consumer's desires and preferences, except where decisions on this basis may be unsafe.
Question 5.9 9.10 and 9.11: Criminal offences, Civil penalties and compensation orders	
Should NSW introduce new criminal offences to deal specifically with abuse, exploitation or neglect committed by a guardian or financial manager? Should NSW introduce new civil penalties for abuse, exploitation or neglect committed by a guardian or financial manager? Should NSW legislation empower the NSW Civil and Administrative Tribunal to issue compensation orders against guardians and financial managers?	There seems wisdom in having these power within the Act.
7. Advocacy and investigative functions	
Question 7.1: Assisting people without guardianship orders	
Should the *Guardianship Act 1987* (NSW) empower the Public Guardian or a public advocate to assist people with disability who are not under guardianship?	The Public Guardian or a public advocate should be able to assist people with a disability who are not under guardianship. Yes the Guardianship Act 1987 (NSW) should be amended to empower the Public Guardian or a public advocate to undertake some forms of systemic advocacy. The role of Public Advocate should be separate from the role of Public Guardian.
Question 7.2: Potential new systemic advocacy functions	

Questions	Our Position
What, if any, forms of systemic advocacy should the *Guardianship Act 1987* (NSW) empower the Public Guardian or a public advocate to undertake?	We suggest the following roles of the Public Guardian or a separate Public Advocate in relation to systematic advocacy. Namely: • Recommending new programs, or improvements to existing programs, to meet the needs of people who need assistance with decision making and to encourage them to reach the greatest practicable degree of autonomy. • Promoting the provision of services and facilities. • Monitoring and reviewing services and facilities with particular attention to the implementation and operation of the NDIS. • Supporting and encouraging the development of programs and organisations that assist people with disability and those that need assistance with decision making. • Promoting the protection of people with impaired capacity from neglect, exploitation and abuse. • Speaking for and promoting the rights of people with disability or impaired capacity. • Supporting and promoting the interests of the carers of people with disability. • To investigate, report and make recommendations on any aspect of the NSW guardianship legislation, and programs to support people in need of assistance with decision making, that the relevant minister refers to them.
Question 7.3: Investigating the need for a guardian	
Should the *Guardianship Act 1987* (NSW) empower the Public Guardian or a public advocate to investigate the need for a guardian?	Yes. The Public Guardian in NSW or a Public Advocate should have the power to investigate any complaint or allegation that a person, who appears to the Public Guardian to have a decision-making disability, is in need of a guardian.

Questions	*Our Position*
Question 7.4: Investigating suspected abuse, exploitation or neglect	
Should the *Guardianship Act 1987* (NSW) empower the Public Guardian or a public advocate to investigate suspected cases of abuse, exploitation or neglect?	Yes. The Public Guardian or a Public Advocate should have the power to investigate any complaint or allegation that a person, who appears to the Public Guardian to have a decision-making disability, is being exploited, neglected or abused.
Question 7.5: Investigations upon complaint or "own motion"	
If the Public Guardian or a public advocate is empowered to conduct investigations, should they be able to investigate on their own motion or only if they receive a complaint?	The Public Guardian or Public Advocate should be able to investigate on its own motion and should not be restricted to those instances where they receive a complaint. There should be simple and easy mechanisms for individuals to raise one-off issues related to individuals or systemic issues with the Public Guardian or Advocate.
Question 7.6: Powers to compel information during investigations	
What powers, if any, should the Public Guardian or a public advocate have to compel someone to provide information during an investigation? What powers of search and entry, if any, should the Public Guardian or a public advocate have when conducting an investigation?	The Public Guardian and/or the Public advocate should have reserve powers related to the provision of information and for search and entry necessary for these bodies to conduct their investigative responsibilities. These should be reserve powers only and used sparingly and, it is anticipated, rarely.
Question 7.8: A new Public Advocate office	
Should NSW establish a separate office of the "Public Advocate"? If so, what functions should be given to this office-holder?	Yes, there should be established in NSW the role of a Public Advocate, which undertakes systematic advocacy and can investigate complaints or allegations concerning a particular adult with impaired capacity. This office should, ideally, be

Questions	Our Position
	separate from but complimentary to the Public Guardian. However, we recognise that the introduction of a separate office of the Public Advocate may have political and resource implications. Should the decision be made not to establish a separate office of the Public Advocate then the powers and functions recommended above should be introduced into the role of the Public Guardian.
Question 8.7: Representation of a client with impaired capacity	
Should the *Guardianship Act 1987* (NSW) or the *Civil and Administrative Tribunal Act 2013* (NSW) allow a person to be represented by a lawyer in Guardianship Division cases when the person's capacity is in question?	

Questions	Our Position
8. Procedures of the Guardianship Division of the NSW Civil and Administrative Tribunal	
Question 8.1: Composition of the Guardianship Division and Appeal Panels (1) Are the current rules on the composition of Guardianship Division and Appeal Panels appropriate? (2) If not, what would you change?	We have no specific recommendations to make on the composition of the Guardianship Division or the Appeals Panels. However we note the concerns of some stakeholders on the skills and knowledge of the panel members and would support reforms that ensure that Division and Panel members have the background and skills they need.
Question 8.2: Parties to guardianship and financial management cases	
(1) Are the rules on who can be a party to guardianship and financial management cases appropriate? (2) If not, who should be a party to these cases?	We are not aware of any changes that are needed to the current practices on who can be a party to hearings.

Question 8.3: The requirement for a hearing	
When, if ever, would it be appropriate for the Guardianship Division to make a decision without holding a hearing?	We have heard of cases of abuse where a person with limited or impaired decision making capacity is induced to agree to a decision that may not be their preference or in their best interest but appear to be giving their consent feely. For these reasons we are of the view that decisions made without a hearing should be the exception and only occur where there is no possibility of coercion, abuse or other undesirable pressure on the person of concern to express a particular view to the tribunals outside of a hearing.
Question 8.4: Notice requirements	
(1) Are the current rules around who should receive notice of guardianship and financial management applications and reviews adequate? If not, what should change? (2) If people who are not parties become entitled to notice, who should be responsible for notifying them?	We are aware of cases of abuse where the family member instigating the abuse has succeeded in becoming the substitute decision maker without the knowledge of other members of the family. In other circumstances partners of long term same sex, and other non-marital, relationships may be excluded from proceedings. For these reasons we believe it is essential that as many persons who may have a legitimate relationship with the person of concern have the opportunity to put their arguments to the tribunal. Privacy concerns, while important, should also be considered alongside the risk of appointing an inappropriate guardian or manager and where the decisions of the tribunal are in the public domain. The responsibility for notification rests with the tribunal.
Question 8.5: When a person can be represented	
When should a person be allowed to be represented by a lawyer or a non-lawyer?	The NSW Mental Health Review Tribunal allows persons to be represented by a lawyer or non-lawyer, subject to the agreement of the tribunal. Our view is that this allows the person before the tribunal, and their carers, to experience a more positive approach to the decisions of the tribunal. Some persons who have been before the MHRT have afterward expressed their view that they did not fully understand what was happening and would have preferred to have been represented or supported. For this reasons we believe that a person before the Guardianship Tribunal or Panels

	should have the right to be represented although this should be optional and the Tribunal should continue to foster an informal an atmosphere for hearings.
Question 8.6: Separate representatives	
How should separate representation be funded?	The Tribunal should be able to order that the costs of representation provided by Legal Aid NSW be paid from the person's estate.
Question 8.7: Representation of a client with impaired capacity	
Should the Guardianship Act 1987 (NSW) or the Civil and Administrative Tribunal Act 2013 (NSW) allow a person to be represented by a lawyer in Guardianship Division cases when the person's capacity is in question?	It seems reasonable that where the capacity of a person involved in a Guardianship Division action is in question, which would be in a large percentage of cases, the person should be able to have a legal representative. The conduct of the Mental Health Review Tribunal may provide some model for this question.
Question 8.8: Timeframes for finalising Guardianship Division cases	
What, if any, changes to the legislation are required to support the timely finalisation of Guardianship Division cases?	Resource issues should not influence the consideration of appropriate amendments to the Act. The Act should be amended to require cases to be completed within a certain time period – say 21 days irrespective of the increase costs to government. Provisions could be inserted into the Act if it is thought that this period is insufficient in specific cases should all the parties agree. In these cases application could be made, either by the tribunal or a party to the case. Provisions should also be built into the Act to prevent any unreasonable delay in the commencement of a case.
Question 8.9: Appealing a Guardianship Division decision	
(1) Is the current process for appealing a Guardianship Division case appropriate and effective? (2) If not, what could be done to improve this process?	We are not aware of any difficulties with the current appeals process.
Question 8.10: Privacy and confidentiality	
What, if anything, should be changed in the law to protect the privacy of people involved in Guardianship Division cases?	We are not aware of any changes that are needed to protect the privacy of persons involved in Guardianship cases.
Question 8.11: Access to documents	

(1) Who should be allowed to access documents from Guardianship Division cases? (2) At what stage of a case should access be allowed?	We are not aware of any changes to the current arrangements for access to documents held by the Tribunal.

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Many thanks for considering our response to your discussion papers on this important review of the Guardianship Act 1987. We would welcome the opportunity to further discuss our views with you should the opportunity arise. Our contact details are provided below.

Yours Sincerely

Jonathan Harms,

CEO, Mental Health Carers NSW

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5 June 2017

Re: Question Paper 5 and 6

Dear Sir/Madam

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Thank you for providing the opportunity to us to comment on the review of the Guardianship Act 1987 (NSW) in April 2016 and for this opportunity to comment on Question Paper 5 Medical and Dental Treatment and Restrictive Practices and Question Paper 6 Remaining Issues. We have noted the format of the questions detailed in this 'question papers' and have structured this paper to respond to the questions raised. We have focused our responses to the matters raised in Question Paper 5 as this is most relevant to our constituency. We will leave it to others to provide feedback on the procedural matters raised in Question Paper 6.

Our overall Observations and Recommendations

Capacity to give consent

We have argued in previous submissions that the definition of consent in the current Act may be limited when applied to a person with a mental illness as it includes only capacity to understand and to indicate preference. A mentally ill person may have the capacity to understand the question that is put to them in terms of a medical treatment and to communicate their preference, however, due to the nature of their mental illness they may lack the capacity to take into consideration the risks associated with that preference. This may occur, for example, when the person suffers from a delusion concerning particular medications, although these medications may be life saving for an afflicting medical condition. The lack of capacity to consider risks can be temporary and fluctuating. Therefore it would seem appropriate for the issue of consent to include the assessment of risk associated with a decision to refuse to, or to agree to, undertake a medical procedure.

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Withholding life support

The principle on which the decision making process should apply is that the alternative decision maker appointed by the Tribunal is empowered to make decisions on behalf of the person for whom they are responsible, including decisions to remove life support or life sustaining treatments. Consequently we suggest that the following words be added to the second clause as indicated below.

> (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, ***and to relieve suffering.***

However, we have noted that differences can arise between guardians, other stakeholders and clinicians and for this reason recommend that the Tribunal be given powers to hold hearings at short notice concerning disputes between the parties arising over the care of people at the end of their life.

Recognition of Advance Care Directives

Even though case law indicates that the Act allows for the recognition of advance care directives, the Act should be amended to specifically recognise advance care directives. The Act should clearly state that an advance care directive takes precedence over the views of enduring and appointed guardians, other persons responsible and treating medical practitioners.

Consent to participate in clinical trials.

We believe that the requirement of the tribunal to approve clinical trials that involve persons for whom a guardian has been appointed is no longer necessary as all clinical trials in NSW are approved by an appropriately convened Ethics Committee. The considerations required by the Tribunal under the current Act appear to duplicate those that would normally be contained in research protocols considered by Ethics Committees where consideration is given to the consent process of substitute decision makers. Thus the requirement of a duplicate approval by the Tribunal, which arguably may not be the most appropriate body to approve a clinical trial, appears to place an unnecessary burden on researchers and clinicians. If a clinical trial of whatever nature has been approved by an Ethics Committee, consent for a person with limited capacity to participate should then rest with the substitute decision maker or guardian and no further approvals should be required by the Tribunal.

Restrictive Practices

There is a need for a consistent approach across NSW for the application of restrictive practices that will be distinct from but complimentary to the principles rolled out as part of the NDIS. The Guardianship Act may not be the most appropriate place for regulating restrictive practices because many of the places where restrictive practices may be applied, such as mental health facilities, aged care homes and private dwellings, may be beyond the scope of the Act. A multipronged approach including policy and procedure, education of clinicians, paid and non-paid carers, and addressing environmental factors, may be the most appropriate. However, we believe there is a need to

implement a consistent approach to collecting data and monitoring practice across all services (both government and non-government where restrictive practices may apply). The collection of data on restrictive practices within mental health facilities in NSW, although not always perfect in its current operation, may provide a basis for constructing a consistent approach to data collection. These data, when analysed and monitored, will inform future policy, education and environmental reforms.

There is also a need for some clarification of the nature and type of restrictive practice for which approvals from a tribunal is needed and those that can be made by the person responsible for care or providing care or treatment. The interpretation of physical restraint (which can be very short term), chemical restraint (and the difference with treatment) and environmental restraint (to exclude sensible practice such as locking doors to protect sensitive records or limit access to harmful objects) needs to be clearly defined.

MHCN mental health carers

Question Paper number 5:

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?	In our submission last year in relation to Question 1 we argued that the definition of capacity should take into consideration the concept of risk. We argued that a mentally ill person may have the capacity to understand the question that is put to them in terms of a medical treatment but may lack the capacity to take into consideration the risks associated with that treatment due to the nature of their mental illness. The lack of capacity can be temporary and fluctuating. Therefore it would seem appropriate for the issue of consent to include the assessment of risk to refuse to or to agree to undertake a medical procedure. This dilemma is reflected in the case a person with a mental disability for whom ECT is recommended due to a recurrence of their mental illness. That mental disability and mental illness may not prevent them from understanding the nature of the treatment and does not make them incapable of indicating if they consent but it may prevent them from making a decision that considers all the risks involved and for this reason may make them incapable of making an informed consent. Therefore the definition of consent should include the concept of risk.
(2) Should the definition used to determine if someone is capable of consenting to medical or dental treatment align with the definitions of capacity and incapacity found elsewhere in the Guardianship Act 1987 (NSW)? If so, how could we achieve this?	Yes there should be internal consistency in the Act in relation to the definitions of disability and consent. Where possible the concepts of consent contained in other NSW legislation, such as the mental health act, should be consistent.

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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?	The principle on which the decision making process should apply is that the alternative decision maker appointed by the Tribunal is empowered to make decisions on behalf of the person for whom they are responsible, including decisions to remove life support or life sustaining treatments. Consequently we suggest that the following words be added to the second clause as indicated below. (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, ***and to relieve suffering.*** However, we have noted that differences can arise between guardians, other stakeholders and clinicians and for this reason recommend that the Tribunal be given powers to hold hearings concerning disputes between the parties at short notice.
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?	The Act needs to be bought up to date to reflect medical practice that was not possible or commonplace when it was drafted. The Act should allow a substitute decision maker to make decisions for the removal of human tissue for the benefit of others where the procedures is limited on its impact on the donating individual. The test of desires and preferences should be used in preference to 'best interest' where the assessment is based on what the person would want if they had the capacity to make decisions.

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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?	The Act should be expanded to include treatment provided by a registered health practitioner so that patients who lack the capacity to consent are not prevented from receiving a wide range of health treatments.
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?	The Act should allow the substitute decision maker to consent to care being provided by non-registered health practitioners subject to an assessment of the level of risk. This should allow for care by such practitioners such as masseurs or aroma therapists etc., where the assessment is made that the care may be beneficial and within what the person would desire. In the re-drafting of the Act it is important that such care is not defined as 'treatment' and thus be prevented by the fact that it is not provided by a registered health professional.
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?	We have no difficulty with the current provisions of the Act in relation to 'special treatments'.

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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?	The reasons for consenting to major treatments should be expanded to include the 'relief of suffering' as was a 'promoting or maintaining the health and wellbeing of the patient'. We do not feel that 'testing for HIV' should still be considered a 'major treatment'. The inclusion in the definition of 'major treatment' of • 'giving an addictive drug • giving a … sedative (with some exceptions) • giving a restricted substance to affect the central nervous system (with some exceptions)' would appear too restrictive when considering the use of medications for people who are mentally ill or have a psychosocial disability, where accepted medications often fall into these categories. It is noted that the use of ECT would only be captured in the current definition as it is generally associated with a general anaesthetic but is not covered by other definitions of major treatment.
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?	We see no issues with the provisions of the Act in relation to consent for minor treatment.

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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?	See comments above in relation to care provided by non-registered health practitioners.
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?	Yes the legislation is clear as to who can consent on behalf of the person with limited decision making capacity. For practical purposes there appears to be little practical difference between the considerations that need to be taken into consideration between major and minor consent.
Question 4.6: Person responsible	
(1) Is the "person responsible" hierarchy appropriate and clear? If not, what changes should be made?	We are not aware of any difficulties with the hierarchy of responsible persons currently in the Act.
(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?	The factors that need to be taken into consideration appear to be adequate.
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?	Modern hospital practices require a responsible person to sign a consent form for even minor procedures. It seems unnecessary to require a special practice for a person with limited capacity as long as the person responsible is able to sign the consent form.
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?	Our views on supported decision making were expressed in our response to Question 2 and these apply equally to this issue.
(2) If so, what should the features of such a scheme be?	

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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?	We are of the view that the decision-making principles in the Protocol for Special Medical Procedures (Sterilisation) adopted by the Australian Guardianship and Administration Council in 2009 appear adequate for this purpose and the Act should be drafted to reflect these principles.
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?	The matters outlined in the discussion paper appear to be adequate to guide the drafting of this section of the revised Act.
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)?	We do not have any other matters to suggest that should not be taken into account other than those in the discussion paper.
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?	Yes, even though case law indicates that it does the Act should specifically recognise advance care directives. The Act should clearly state that an advance care directive takes precedence over the views of enduring guardians, other persons responsible and treating medical practitioners.
Question 4.14: Who can make an advance care directive	
Who should be able to make an advance care directive?	The definition of the South Australian legislation appears to be a suitable one for the NSW Act: namely a “competent adult” can make an advance care directive if they understand what an advance care directive is and the consequences of making one.

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Question 4.15: Form of an advance care directive	
What form should an advance care directive take?	The Act should not specify the form of an advance care directive. There should continue to be a variety of ways that a competent adult can give a directive and should seek to facilitate their input and wishes whenever possible and reasonable. We would be particularly opposed to the requirement that it be on a specific form, that it be written in English and that a doctor's certificate should accompany it.
Question 4.16: Matters an advance care directive can cover	
What matters should an advance care directive be able to cover?	An advance care directive should be able to include instructions on quality of life factors such as accommodation and personal care as well as the instruction to refuse care of any kind or to stop care even if that care was necessary to prolong life. The advance care directive should continue to give direction to the enduring guardian or an appointed guardian. Any guardian should be required to recognise the person's values and preferences as the basis for making medical decisions whether specifically stated or implied in the advance care directive.
Question 4.17: When an advance care directive should be invalid	
In what circumstances should an advance care directive be invalid?	In addition to the examples provided in the discussion paper of circumstances where the advance care directive may not be invalid, we would like to add a specific example which recognises the mental state of the person at the time the advance care directive was written. Recognition should be given to circumstances where a mentally ill person writes an advance care directive or gives verbal instructions when they are in a manic state or a depressive state. In such circumstances the advance care directive many not reflect the values and preferences they would express when they were not suffering from the mental illness.

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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?	We are not aware of any need to change the offences under the Act.
5. Clinical trials	
Question 5.1: Definition of "clinical trial"	
How should the Guardianship Act 1987 (NSW) define "clinical trial"?	Notwithstanding the suggestion to broaden the definition of research it is difficult to understand why the Tribunal is required to approve a clinical trial when a recognised ethics committee has already approved it. If a substitute decision maker can give approval for medical or other treatment of a similar nature to that which would be given in a clinical trial there does not seem a good reason why there is a need for the second level of approval by the tribunal. This is especially the case when the tribunal may not be the most appropriate body to cast judgement on the benefits or otherwise of a 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?	Yes there should be more than one level of medical research as the definition of 'medical or dental' treatment as currently expressed in the Act appears too narrow. This was discussed above and it should be recognised that research may also be undertaken by health professionals such as nurses, physiotherapists and psychologists, and that such research could also be potentially harmful to the participants. However if we remove the requirement for the Tribunal to approve clinical trials and leave this matter up to Ethic Committees and the substitute decision maker the question is no longer relevant.

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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?	These questions have already been addressed in the comments above.
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?	A person should always have the right to object to participation in research, even when they have limited capacity to understand the nature of the research and its risk and benefits.
Question 5.5: Preconditions for consent	
What preconditions should be met before a decision-maker can consent to participation?	The preconditions for consent are those that would need to be met by an Ethic Committee and it may not be necessary for them to be again spelled out in the Act.
Question 5.6: Requirements after consent	
What should researchers be required to do after consent is obtained?	The requirements placed on researchers are normally spelt out in the research protocol which is approved by an appropriately appointed ethics committee and does not need to be spelt out again in the Act.
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?	As we have argued that the second layer of approval by the tribunal appears unnecessary the question of waiver is immaterial.
Question 5.8: Other issues	
Do you have any other comments about the consent requirements for clinical trials?	N/A

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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?	The Mental Health Act should take precedence over the Guardianship Act where decisions are made to admit or discharge a patient from a designated mental health facility. We agree that the Mental Health Review Tribunal should be the decision-maker for all medical decisions in circumstances where a person is detained in a mental health facility, although consumer and carers views should be considered and carers with or without Guardianship authority should be included along with consumers in Tribunal processes, but will have an additional responsibility to help communicate consumer needs and wishes if they do have Guardianship.
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?	We agree there is a need for the Act to clearly cover the relationship between it and the Forensic Provision Act. This may be to provide guidance to the approach taken by the tribunal in appointing a guardian to meet the conditions under the Forensic Provisions Act.
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?	Considerations should be given to amendments to both the Mental Health Act and the Guardianship Act where there is recognition of differing meanings between the Acts, for example in the case of termination of pregnancy. This may require the Mental Health Review Tribunal to take into consideration the tests required under the Guardianship Act before making a determination.

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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?	The problems with the regulation of restrictive practices are that there are different bodies responsible for monitoring and regulating restrictive practice in NSW. There is a lack of clarity in some definitions of restrictive practice such as the use of medications to control behaviour and the confusion over the concepts of 'chemical restraint' and how it differs from 'treatment'. There are gaps in relation to the application of a consistent set of rules related to restraint particularly across aged care facilities and care at home and in non-government facilities. Ultimately, all forms of involuntary hospitalisation are restraint and therefore potentially traumatising, increasing risk of suicide and exacerbation of symptoms subsequently, which means the need to expand community treatment so as to avoid the need for hospitalisation is an urgent imperative.
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?	There is a need for a consistent approach across NSW for the application of restrictive practices that will be distinct from but complimentary to the principles rolled out as part of the NDIS. The Guardianship Act may not be the appropriate place for regulating restrictive practices because many of the places where restrictive practices may be applied, such as mental health facilities, aged care homes and private dwellings, are beyond the scope of the Act. A multipronged approach including policy and procedure, education of clinicians, paid and non-paid carers, and addressing environmental factors may be the most appropriate. However, we believe there is a need to implement a consistent approach to collecting data and monitoring practice across all services (both government and non-government where restrictive practices may apply). The collection of data on restrictive practices within mental health facilities in NSW, although flawed in its

	current operation, may provide a basis for constructing a consistent approach to data that will inform future policy, education and environmental reforms.
Question 7.3: Who should be regulated?	
Who should any NSW regulation of the use of restrictive practices apply to?	7.28 NSW legislation and policy should 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. There is a role for the Guardianship Act in such legislation and policy as it has coverage over people in NSW with reduced decision making capacity and at risk of suffering restrictive practices regardless of the location.
Question 7.4: Defining restrictive practices	
How should restrictive practices be defined?	The definitions of restrictive practices in the NDIS Quality and Safeguarding Framework appears to be a good start for debate on restrictive practices. However, the definitions of 'psycho-social restraint' and 'consequence driven practices' may need to be carefully constructed least they create confusion with accepted behaviour modification treatments and practices.
Question 7.5: When restrictive practices should be permitted	
In what circumstances, if any, should restrictive practices be permitted?	The rationale for the use of restrictive practices as outlined by the NSW Trustee and Guardian solely to 'protect the person's safety and interest' appears to be somewhat limited as restrictive practices may in some circumstances, such as shared living arrangements, be necessary to protect others, such as residents or patients and staff.
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?	There is a need for some clarification of the nature and type of restrictive practice for which approvals from tribunals is needed and those that can be made by the person responsible for care or providing care or treatment. For example, gentle physical guidance which can be characterised as 'physical restraint' may be momentarily required to direct a cognitively impaired person from leaving the

(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?	facility, to prevent someone from hitting another or to stop short term destructive behaviour involving throwing objects. In such situations the approval of a tribunal is impractical. Other forms of restrictive practice, for example, long term housing in a locked facility, lend themselves more readily to the requirement for Tribunal approval. As mentioned above the distinction between chemical restraint for controlling behaviour and treatment for the purpose of reducing harmful behaviour can be a grey area much open to interpretation. Care is also needed on the clarification of what types of 'psycho-social', 'environmental' and 'consequence driven practices' will require tribunal approval. Considering the inclusion of 'environment' restrictive practice, some guidelines may be needed on difference practices. For example, some staff may need guidance on the difference between locking the door to cupboards and rooms containing dangerous objects or sensitive personal files to prevent entry by residents and restricting 'a person's free access to all part of their environment' (as suggested in 7.29 of the discussion document).
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?	The maintenance of a register at the facility or unit level to record incidents of restraint or seclusion may be one mechanism for increasing accountability on the use of restrictive practices on a day to day basis. This register should be subject to inspection and validation by person from an independent authority, as is required in mental health facilities in NSW, and cross checked against any other reporting mechanisms. From such a register regular reporting to a central authority may provide some safeguards to the appropriate use of restrictive practise 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?	Ideally all persons in care or subject to a guardianship order where there is the history of disruptive behaviours should have a care plan in place which includes a behaviour support component.

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Many thanks for considering our response to your discussion papers on this important review of the Guardianship Act 1987. We would welcome the opportunity to further discuss our views with you should the opportunity arise. Our contact details are provided below.

Yours Sincerely

Jonathan Harms,

CEO, Mental Health Carers NSW

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