MHCN mental health carers

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

www.lawreform.justice.nsw.gov.au

5 June 2017

Re: Question Paper 5 and 6

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 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.

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.

MCHN Mental Health Carers NSW Inc.
Funded by the NSW Mental Health Commission
Suite 501, Level 5, 80 William St, Woolloomooloo, NSW, 2011
Carer Connection Helpline: 1300 554 660 – Free Call
P: (02) 9332 0777
W: www.arafmi.org
E: admin@arafmi.org

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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

[redacted]

Jonathan Harms,

CEO, Mental Health Carers NSW

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