Being

Review of the Guardianship Act 1987:

Submission for Question Paper 5 to the Law Reform Commission of NSW

30 May 2017

Being

***Being* is the independent, state-wide peak organisation for people with a lived experience of mental illness (consumers). We work with consumers to achieve and support systemic change.**

Being's vision is for all people with a lived experience of mental illness to participate as valued citizens in the communities they choose. Participation is a fundamental human right as enshrined in Article 25 of the International Covenant on Civil and Political Rights (ICCPR). We work from the premise that the participation of consumers results in more effective public policy and facilitates individual recovery.

Our work is guided by eight principles:

- Principles of recovery underpin all our work
- Recognition of the importance of a holistic approach
- Collaboration and team work
- Flexibility, responsiveness and innovation
- Consultative and participatory processes that have consumers at the centre
- Promoting equity and positive images to address discrimination and prejudice
- Accessible and approachable for all
- Promotion of professionalism and quality practice

Being is an independent non-government organisation that receives core and project funding from the Mental Health Commission of NSW.

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Being would like to thank the people who have generously shared with us their experiences and views.

Being

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Introduction

Being is pleased to comment on Question Paper 5 for the Review of the Guardianship Act 1987 NSW (the Guardianship Act) by the NSW Law Reform Commission (the Commission).

We have responded to the following sections of Question Paper 5[1]:

- A formalised supported decision-making structure and its application to medical and dental decisions
- Consent for medical and dental treatment with a focus on consent for sterilisation and termination of pregnancies
- The relationship between the Mental Health Act and the Guardianship Act
- Advance care planning
- Restrictive practices.

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?

Being supports the definition proposed by the NSW Disability Network Forum in response to Discussion Paper 1[2].

[1] Please note throughout this submission we use the terms "consumer" and "person with a mental illness" interchangeably to refer to people living with mental illness. We refer to people receiving assistance with decision-making as "consumers" or "decision-makers", and refer to those providing support as "supporters" or "co-decision-makers".

[2] NSW Disability Network Forum (2016). Review of the Guardianship Act 1987: Response to Question Paper 1. Retrieved from: https://www.ncoss.org.au/sites/default/files/public/policy/161013%20DNF%20Guardianship%20submission%20-%20response%20to%20QP1%20final.pdf

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?

Being recommends that any definitions of capacity and incapacity used elsewhere in the Guardianship Act also extend to any medical or dental treatment. We also recommend that the definitions of capacity and incapacity under the Guardianship Act, be aligned with any definition and assessment under the Mental Health Act.

Supported decision-making

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?

Being strongly supports a formal supported decision-making scheme under the Guardianship Act[3]. This model is strongly aligned with recovery-oriented principles used in the mental health field, and recommended by the Australian Health Ministers' Advisory Council[4]. Many consumers are able to make decisions, but may require support to do this. It is also important to note that people with a mental illness often have fluctuating capacity to make decisions and this needs to be taken into account when considering issues around consent.

If a formal supported decision-making scheme is put into place under the Guardianship Act, all aspects of medical and dental procedures, including special treatment, major treatment and minor treatment should be covered by the scheme. Advanced care plans or wellness plans should become the decision-making tool if someone lacks consent, but has a plan outlining their wishes.

Many people with a mental illness that we have spoken to advised us that at times they have lacked the capacity to make decisions regarding medical treatment at the beginning of treatment; however, during treatment they have regained that capacity

[3] Being (2017). Review of the Guardianship Act 1987: Submission for Question Paper 2 to the Law Reform Commission of NSW

[4] Australian Health Ministers' Advisory Council (2013). *A National Framework for Recovery Oriented Mental Health Services: Guide for Practitioners and Providers.* Retrieved from: http://www.mhima.org.au/pdfs/Recovery%20Framework%202013_Guide_practitioners_providers.pdf

but have been unable to change the treatment decision. Frequent assessment of capacity should be made for each medical decision, and throughout medical treatment. If at any time capacity is regained, a person should be able to withdraw consent for medical treatment, regardless of whether a doctor believes that it is in the 'best interest' of the person. If a person without a disability, or mental illness is able to make a decision that a doctor disagrees with, without being forced to have treatment, then someone with mental illness should also have that right.

Recommendations:

1. That medical and dental treatment decisions be part of any formal decision-making scheme under the Guardianship Act
2. That issues surrounding fluctuating capacity for people with mental illness are taken into account when considering issues to do with consent
3. That assessment for decision-making capacity and consent to treatment should occur for every medical decision, and that decision-making capacity and consent to treatment is assessed throughout medical treatment
4. If someone has been assessed as having capacity during treatment, and withdraws consent, that decision not be overruled by a guardian or medical professional even if treatment is deemed to be in the "best interest" of the person.

Sterilisation

Question 4.10 Consent for sterilisation

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

Many people have told us that no person with mental illness should be subject to a procedure that may render them infertile, or result in a termination of pregnancy without their consent. In our view this is in breach of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) Article's 3, 12 and 15[5]. We would endorse the World Health Organizations view that "any procedure resulting in sterilisation must be provided on the basis of full, free and informed consent". [6] Given the issue of fluctuating capacity, it is likely that many people with a mental illness will

[5] United Nations (2006). *Convention on the Rights of Persons with Disabilities*, New York, United States.
[6] World Health Organization, *Eliminating Forced, Coercive and otherwise Involuntary Sterilization: An Interagency Statement* (2014) 6 cited in Discussion Paper 5.

at some point have capacity to make an informed decision, either independently or with support.

Being understands that the Guardianship Act is applicable for people with a number of disabilities, and the elderly, along with people with a mental illness. We recommend that legislation be tailored to suit varying situations, rather than one rule fits all, while upholding people's human rights.

If a person, after attempts to support them to make their own decision regarding sterilisation or termination of a pregnancy, and that person is deemed to lack capacity, and a sterilisation or termination is regarded as necessary, then only a Tribunal should have the authority to make that decision.

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?

Please see our response to questions 4.13, 4.14, and 4.16.

Recommendations:

5. That legislation about sterilisation be tailored to suit varying situations, taking into account fluctuating capacity, while upholding people's human rights.
6. That advanced care directives have the power to include decisions surrounding termination of pregnancies, and procedures that may result in sterilisation.

Question 4.11: Preconditions for consent to sterilisation

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

If a matter about sterilisation does get referred to the Tribunal for a decision, after attempts to support a person with a mental illness to make that decision themselves, the Tribunal should be mandated to take into account any other possible options, including temporary sterilisation methods as per the Queensland legislation[7].

Currently the Tribunal must be satisfied that sterilisation is:

- the most appropriate form of treatment for promoting and maintaining the persons health and wellbeing, and

[7] *Guardianship and Administration Act QLD (2000).* Section 70 (3) (a). Retrieved from: https://www.legislation.qld.gov.au/LEGISLTN/CURRENT/G/GuardAdminA00.pdf

- necessary to save the persons life or prevent serious damage to the persons health.

If the ability to sterilise someone without their consent remains in the Guardianship Act, *Being* supports, the second of the two conditions:

- necessary to save the persons life or prevent serious damage to the persons health.

Recommendations:

7. That the overriding principle surrounding termination of pregnancy and sterilisation uphold international human rights conventions
8. That if a matter does get referred to the Tribunal, every possible step to find alternative options should be taken
9. If the ability to sterilise someone without their consent remains in the Guardianship Act, then the Tribunal must be satisfied that the procedure is necessary to save the persons life or prevent serious damage to the persons health.

Advance care directives

4.13. Should legislation explicitly recognise advance care directives? If so, is the Guardianship Act 1987 (NSW) the appropriate place to recognise advance care directives?

Advance care directives allow people who have fluctuating capacity to make decisions for themselves and maintain their autonomy and security when they are unwell. These wishes are far more likely to be followed if they are written down, compared to being verbally told to someone.

They are a vital tool for people with mental health issues and need to be recognised in legislation. The law is currently unclear about advance care directives in NSW, which causes confusion and stress for people who wish to use this tool. The law needs to be clarified and brought into line with other states, which already recognise advanced care directives.

Being often hears from people who want advance care directives that can be used when they are unwell, and we know this is the case in other countries as well. For some people, this is so their financial affairs can continue to be taken care of when they go into hospital or when they have a reduced decision-making capacity. For others, this is so they can ensure they get the medical treatment they have chosen,

even when they are not able to advocate for it. Having these directives in place can make the experience of being unwell much less stressful and reduce the obstacles on a person's recovery journey.

For these documents to be meaningful, there must be consequences for them not being followed. The law should include mechanisms to hold services accountable for situations where advance care directives are not followed or followed incorrectly. For example, in Victoria a treatment team must consider an advance statement, and must provide written reasons if they do not offer the treatment requested.

Recommendations:

10. The Guardianship Act to recognise advance care directives.
11. The Guardianship Act to outline the ramifications when advance care directives are not followed.

4.14. Who should be able to make an advance care directive?

Anyone who has capacity at the time of preparing the document should be able to make an advance care directive. This capacity could be confirmed by a letter from a General Practitioner or psychiatrist, as is the case in other states.

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

An advance care directive should be able to cover any topic that a person requires, including financial, housing, medical treatment decisions – including termination of pregnancies. People should also be able to use these documents to nominate a substitute decision-maker to come into effect if they should have reduced capacity.

In addition, we suggest that the concept of advance care directives be expanded to include much of the content of wellness plans. This is a plan written by a person with a mental health issue in consultation with their support network and medical team. People use these plans to:

- Identify signs they are becoming unwell
- Provide advice on what can help when they are becoming unwell
- List people who can be contacted in particular situations
- Record what should happen if they become unwell. For example, what hospital they want to go to and what they want to take with them
- List medications.

These plans help medical teams and friends and family know what a person wants when they become unwell. The process of making the plan can also help a person think through what help works for them and build stronger connections with their support networks.

> Jenny has had periods of being unwell for a number of years. She has a wellness plan she has shared with colleagues at work, her friends and her doctors. Because of this, they know how to recognise when she is starting to get unwell and who to contact. She has a pet that is very important to her, and she has previously refused to go to hospital out of concern for her pet. Her wellness plan outlines who should take care of her pet and how they should be contacted, which makes her feel safe to go to hospital.

Research on these plans (an example is the Wellness Recovery Action Plans) has been very positive. A trial in SA found that people had higher self-esteem, more confidence in advocating for themselves and more positive thinking after using wellness plans.

Recommendation:

12. Advance care directives to be able to cover a wide range of topics depending on the preferences of the consumer.

Guardianship Act and the Mental Health Act

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

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

Being believes there is a clear relationship between the Guardianship Act and the Mental Health Act. People with a mental illness at times have reduced decision-making capabilities, and require support to make their own decisions, or in some cases need substitute decision makers. Consumers have told us that the most common times their various decision-making arrangements, whether power of attorneys, formal guardianship orders, financial guardianship orders, wellness plans, or informal supported decision-making arrangements, are put into place is when they are in hospital, particularly as an involuntary patient under the Mental Health Act.

While there is a clear relationship between the two acts, there are many contradictions.

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

Both the Mental Health Act and the Guardianship Act have sections relating to consent to medical treatment. *Being* believes that contradictions will arise if the Guardianship Act has a formal supported decision making framework. If someone has a formal supporter rather than a substitute decision maker, when they are in hospital as an involuntary patient that person and their supporter lose the right to make their own decisions regarding treatment.

Under the Mental Health Act, 'special medical treatment' is defined as meaning "any treatment, procedure, operation or examination that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out"[8], with surgical termination of pregnancy considered to be a surgical operation[9]. Under the Guardianship Act both a termination, and a treatment that is intended or likely to render the patient permanently infertile, are both classified as "special treatment"[10]. This means the questions of capacity, and who has the authority to make a decision are different and can conflict in some cases.

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

The inconsistencies between the Mental Health Act and the Guardianship Act are not unique to New South Wales[11]. *Being* supports both amending the Mental Health Act to ensure there is consistency as recommended by the Victorian Law Reform Commission, and having the Guardianship Act take precedent over the Mental Health Act with regards to decision making arrangements.

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?

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

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[8] Mental Health Act (2007) No 8. Section 98 (a). Retrieved from: http://www.legislation.nsw.gov.au/#/view/act/2007/8/whole

[9] Mental Health Act (2007) No 8. Retrieved from: http://www.legislation.nsw.gov.au/#/view/act/2007/8/whole

[10] Law Reform Commission NSW (2017). Question Paper 5: Medical and dental treatment and restrictive practices p28. 4.5. Retrieved from: http://www.lawreform.justice.nsw.gov.au/Documents/Current-projects/Guardianship/Question-Papers/QP5.pdf

[11] Davidson, G., Kelly, B., Macdonald, G., Rizzo, M., Lombard, L., Abogunrin, O., ... & Martin, A. (2015). Supported decision making: a review of the international literature. *International journal of law and psychiatry*, p38.

Any system of formalised supported decision-making or substitute decision making regarding consent to medical treatment in the Guardianship Act, needs to be consistent in both the Mental Health Act and the Guardianship Act.

As per our response to Question 6.1.3, *Being* supports both amending the Mental Health Act to ensure there is consistency as recommended by the Victorian Law Reform Commission and having the Guardianship Act take precedent over the Mental Health Act with regards to decision making arrangements.

Currently the Mental Health Act allows the Tribunal to approve a termination, even if a person with a mental illness has capacity to make that decision, but is refusing to give that consent[12]. *Being* strongly supports the Guardianship legislation having priority regarding termination which only allows a decision to be made if someone has been deemed to lack capacity. In a circumstance where the person may have a substitute decision-maker, and they do not consent, this decision should not be over-ruled by the Tribunal.

Recommendations

13. That the Mental Health Act be amended to take into account changes to the Guardianship Act regarding supported decision-making and decisions as an involuntary patient in a mental health facility.
14. That the Guardianship Act take precedence over the Mental Health Act with regards to decision making arrangements.
15. That the Guardianship Act and the Mental Health Act align the definitions of "special treatment", and "surgical procedures" for termination of pregnancy and sterilisation.

Restrictive practices

Question 7.1: Problems with the regulation of restrictive practices

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

Being strongly believes that the use of restrictive practices breaches international human rights law, with the exception of when it is necessary to save the persons life or prevent serious damage to the persons health. Article 15 of the United Nations

[12] Mental Health Act (2007) No 8. Section 99 (a) Retrieved from: http://www.legislation.nsw.gov.au/#/view/act/2007/8/whole

Convention on the Rights of Persons with Disabilities (CRPD) states that people with disabilities have a right to be free from torture and cruel, inhuman or degrading treatment or punishment. We hear many stories from people who have been subject to seclusion and restraint in mental health facilities, and of the trauma that causes them.

> Sally is a 40-year-old woman with a lived experience of mental illness and has been restrained and put into seclusion many times during admissions to hospital. Sometimes she felt that the staff used it as a way of controlling people's behaviour, when the hospital environment was the cause of her distress. She reports times where she has been pinned down by more than one staff member, and left in a seclusion room for many hours without being checked on. Sally has also had experiences of seclusion and restraint while in a local police station, when the cause of her needing to be taken to the police station has been due to her mental illness. At those times Sally reports that she was not behaving in a way that would have needed any restraint or seclusion, and was told that it was because she had a mental illness that she had to be restrained and secluded. Sally feels that those experiences were degrading and cruel, and that no person, with or without a disability or mental illness, should be subjected to that treatment.

Currently the NSW Government is undertaking a review into the use of seclusion and restraint in mental health facilities. The findings and recommendations coming out from that review will need to be considered, and incorporated into future regulation.

Recommendation:

16. That the Law Reform Commission investigate and incorporate any findings and recommendations from the NSW Government review into the use of seclusion and restraint in future regulations.

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?

Being supports legislation that explicitly deals with the use of restrictive practices, which has a firm commitment to eliminating restrictive practices in accordance with the CRPD, Article 15.

Many people with a mental illness experience incidents of restrictive practices, without falling under the Guardianship Act. Most commonly people's experience of restrictive practices is in a mental health facility, although they can also experience them in other facilities or situations. For people with a mental illness restrictive practices are not generally used as part of an ongoing behaviour management plan. *Being* strongly opposes any legislation that allows for restrictive practices being used in behaviour management plans.

While in mental health facilities people are covered under the Mental Health Act. If this continues to allow the use of restrictive practices, then the Guardianship Act and the Mental Health act would contradict each other.

If the legislation is going to cover all facilities or situations then it needs to be in different legislation, or it will only apply to people under Guardianship Act. If there was separate legislation against the use of restrictive practices, it could take precedence over both the Guardianship Act, the Mental Health Act, and any policies that the Department of Health or Family and Community Services have.

While *Being* believes that legislation is necessary to ensure human rights are upheld under the law, we also agree that other steps can be taken to reduce and eliminate restrictive practices as noted in Question Paper 5.

Recommendations:

17. That NSW pass legislation explicitly dealing with restrictive practices that is separate to the Guardianship Act and overrules other legislation.

18. That NSW amend the Guardianship Act, Mental Health Act and any policies relating to restrictive practices in all settings to align with Article 15 of the CRPD.

Question 7.3: Who should be regulated?

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

Restrictive practices can occur in many settings. People have told *Being* of many examples where restrictive practices, such as seclusion, physical restraint, and chemical restraint, have been used in inpatient mental health facilities, community mental health settings, residential mental health facilities, hospital emergency rooms, and police stations. Regulation of restrictive practices should apply in any situation where people with mental illnesses may be subject to these practices.

Recommendation:

19. That regulation of restrictive practices should apply in any situation where people with mental illnesses may be subject to these practices.

Question 7.4: Defining restrictive practices

How should restrictive practices be defined?

Being supports the definitions outlined in the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector (the 'National Framework'), other than the definition of "chemical restraint".

Chemical restraint is defined as:

- 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.

Being has heard from many people with a mental illness who feel that medication is used as a form of behavioural control, and that they are regularly overmedicated. It has been reported by people that medication can be increased during times that a mental health ward is under-staffed, or on weekends.

Johns experience:
"I was on so much medication that I couldn't think. I hadn't been doing anything that would mean I should get so much medication. They didn't try to talk to me, explain what was happening, or try to distract me from distressing situations. I feel like it happened more when there were less staff, or lots of people in the unit".

Being is concerned that having the words "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", may allow for chemical restraint of people with mental illness to continue without recourse due to a definition that is too broad. We would recommend looking at strengthening definitions to include clauses about reasonable use of medication for people with a mental illness.

Recommendations:

20. That the definition of chemical restraint includes clauses for reasonable use of medication for people with mental illness rather than a blanket allowance to use for treatment of mental illness, to ensure over medication for behavioural control purposes does not occur.

7.5: When restrictive practices should be permitted. In what circumstances if any?

Being recommends that Australia should work towards eliminating restrictive practices as per the UN Committee's advice. We do acknowledge that there may be times when it is needed; however, the impact upon people and the trauma caused by these practices needs to be of upmost consideration. We agree with the NSW Trustee and Guardians submission that restrictive practices should only be used in exceptional circumstances, for the shortest possible time, and only when necessary to protect the person's best interests. *Being* does not support the use of restrictive practices as a form of planned behaviour control.

Summary of Recommendations

1. That medical and dental treatment decisions be part of any formal decision-making scheme under the Guardianship Act
2. That issues surrounding fluctuating capacity for people with mental illness are taken into account when considering issues to do with consent
3. That assessment for decision-making capacity and consent to treatment should occur for every medical decision, and that decision-making capacity and consent to treatment is assessed throughout medical treatment
4. If someone has been assessed as having capacity during treatment, and withdraws consent, that decision not be overruled by a guardian or medical professional even if treatment is deemed to be in the "best interest" of the person.
5. That legislation about sterilisation be tailored to suit varying situations, taking into account fluctuating capacity, while upholding people's human rights.
6. That advanced care directives have the power to include decisions surrounding termination of pregnancies, and procedures that may result in sterilisation.
7. That the overriding principle surrounding termination of pregnancy and sterilisation uphold international human rights conventions
8. That if a matter does get referred to the Tribunal, every possible step to find alternative options should be taken
9. If the ability to sterilise someone without their consent remains in the Guardianship Act, then the Tribunal must be satisfied that the procedure is necessary to save the persons life or prevent serious damage to the persons health.
10. The Guardianship Act to recognise advance care directives.
11. The Guardianship Act to outline the ramifications when advance care directives are not followed.
12. Advance care directives to be able to cover a wide range of topics depending on the preferences of the consumer.
13. That the Mental Health Act be amended to take into account changes to the Guardianship Act regarding supported decision-making and decisions as an involuntary patient in a mental health facility.
14. That the Guardianship Act take precedence over the Mental Health Act with regards to decision making arrangements.

15. That the Guardianship Act and the Mental Health Act align the definitions of "special treatment", and "surgical procedures" for termination of pregnancy and sterilisation.
16. That the Law Reform Commission investigate and incorporate any findings and recommendations from the NSW Government review into the use of seclusion and restraint in future regulations.
17. That NSW pass legislation explicitly dealing with restrictive practices that is separate to the Guardianship Act and overrules other legislation.
18. That NSW amend the Guardianship Act, Mental Health Act and any policies relating to restrictive practices in all settings to align with Article 15 of the CRPD.
19. That regulation of restrictive practices should apply in any situation where people with mental illnesses may be subject to these practices.
20. That the definition of chemical restraint includes clauses for reasonable use of medication for people with mental illness rather than a blanket allowance to use for treatment of mental illness, to ensure over medication for behavioural control purposes does not occur.