# Review of the Guardianship Act 1987: Question Paper 5

Legal Aid NSW submission to New South Wales Law Reform Commission

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# **Table of Contents**

Ch 3 Capacity to consent to medical and dental treatment	3
Ch 4 Types of medical and dental treatment	3
Ch 4 Consent to medical and dental treatment	4
Ch 5 Clinical trials	6
Ch 6 The Guardianship Act and mental health legislation	7
Ch 7 Restrictive practices	8

# About Legal Aid NSW

The Legal Aid Commission of New South Wales (Legal Aid NSW) is an independent statutory body established under the Legal Aid Commission Act 1979 (NSW) to provide legal assistance, with a particular focus on the needs of people who are socially and economically disadvantaged.

Legal Aid NSW provides information, community legal education, advice, minor assistance and representation, through a large in-house legal practice and through grants of aid to private practitioners. Legal Aid NSW also funds a number of services provided by non-government organisations, including 32 community legal centres and 28 Women's Domestic Violence Court Advocacy Services.

Legal Aid NSW provides civil law services to some of the most disadvantaged and vulnerable members of our society. Currently we have over 150 civil lawyers who provide advice across all areas of civil law.

The specialist Mental Health Advocacy Service of Legal Aid NSW provides representation to clients in the Guardianship Division of the NSW Civil and Administrative Decisions Tribunal (the Tribunal) on a direct representation basis and when the Tribunal orders that the client be separately represented. Solicitors in Legal Aid NSW regional offices also provide representation in guardianship matters.

The Legal Aid NSW Children's Civil Law Service (CCLS), established in 2013, provides a targeted and holistic legal service to young people identified as having complex needs. The CCLS also facilitates representation of its clients in matters before the Tribunal, either through liaising with the young person's separate representative to ensure the young person's views are heard, or directly representing the young person in the proceedings.

Legal Aid NSW provided 614 advice and minor assistance services relating to guardianship to clients in 2015–2016. We also provided 264 representation services in guardianship matters, through both in-house and private practitioners.

Legal Aid NSW welcomes the opportunity to respond to *Question Paper 5: Medical* and dental treatment and restrictive practices.

Should you have any questions about the submission, please contact:

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or

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# Ch 3 Capacity to consent to medical and dental treatment

Legal Aid NSW does not have concerns about the current definitions of 'incapable of giving consent' in the Guardianship Act.

# Ch 4 Types of medical and dental treatment

#### Q3.1 Withholding life-sustaining treatment

Legal Aid NSW notes that some of the Tribunal's decisions appear to be based on an understanding that consent to withdraw treatment is required by law: for example, WK v Public Guardian (No 2).1 Legal Aid NSW prefers the approach taken in Re AG2 which emphasises that consent can be given or refused for treatment. The Tribunal in this case held that a guardian can consent to palliative care, which includes treatment limitations, as long as the care promotes the health and wellbeing of the person, as provided by the Act. Futile treatment could not be considered to promote the person's health and wellbeing.

Legal Aid NSW would support an amendment to make clear that that a guardian can withhold consent to life-sustaining treatment if it is futile, that is, not likely to produce any improvement in the person's health and wellbeing.

#### Q3.2 Removing and using human tissue

Legal Aid NSW considers that a guardian should be able to consent to minimally invasive procedures involving removing and using human tissue if the guardian considers that the procedure will promote the health and wellbeing of the person. These procedures might include DNA testing. However for major interventions such as the collection of semen or organ donations, an order of the Tribunal should be required. Again, the Tribunal should only make such an order if the procedure would promote the health and wellbeing of the person. 'Wellbeing' should be interpreted broadly so that giving effect to a wish to help another would be considered to promote a person's wellbeing.

#### Q3.3 Treatment by a registered health practitioner

The definition of 'medical and dental treatment' should include treatment by a registered health practitioner.

#### Q3.4 Types of treatment covered by Part 5

Legal Aid NSW does not have concerns about the exclusion of treatments from Part 5.

<sup>&</sup>lt;sup>1</sup> [2006] NSWADT 121

<sup>&</sup>lt;sup>2</sup> [2007] NSW GT 1

### Ch 4 Consent to medical and dental treatment

#### Q4.1 Special treatment

The provisions of the *Guardianship Act* regarding consent to medical and dental treatment are complex and restrictive. Legal Aid NSW is particularly concerned that the restricted access to treatments likely to render a person infertile create significant difficulties where a hysterectomy is the only appropriate way of treating severe dysmenorrhoea (painful periods) or menorrhagia (prolonged and heavy periods). Currently, women under guardianship are unable to access hysterectomy for menstrual disorders when this would be the appropriate treatment, because the legislation requires that this procedure only be carried out to save the patient's life or to prevent serious damage to the patient's health (s 45(2)). Two recent applications in the Guardianship Division, *UMG*<sup>3</sup> and *MMW*<sup>4</sup> concerned women who wished to undergo hysterectomy in order to treat painful menstrual disorders, but in circumstances where there was no threat to their life or risk of serious damage to their health. In each case, the Tribunal found that the woman was able to consent to the treatment. However if that capacity did not exist, the Tribunal may have been unable to consent to the treatment on behalf of the woman, despite expert evidence that hysterectomy was the most appropriate treatment.

#### Case Study - UMG

UMG is a 32 year old woman. She has a mild intellectual disability. She has severe endometriosis, experiences heavy and painful periods, sometimes getting her period every two weeks and sometimes bleeding for up to two months. Various treatments have been tried including the contraceptive pill, a contraceptive injection and curettage. She gave evidence before the Tribunal that the pain meant that she was unable to help her aunt and uncle around the house, she was reluctant to socialise or go for walks, and she 'cannot go on feeling like this'. A hysterectomy was recommended by her doctor and she wished to have this treatment. UMG gave evidence that she had never wished to have children. The Tribunal found that UMG was not incapable of giving consent to the treatment.

Legal Aid NSW acknowledges the serious concerns about the sterilisation of women with disabilities for eugenic reasons and for contraceptive purposes. As we note in response to Question 4.12, such considerations should have no part in a decision to consent to treatment that will result in sterilisation. Safeguards need to be in place to protect the reproductive rights of women with disabilities. However the current safeguards can in some instances prevent women with disabilities from obtaining the medical treatment they need. Legal Aid NSW proposes that the Tribunal should be able to consent to special

<sup>3 [2015]</sup> NSWCATGD 54

<sup>4 [2014]</sup> NSWCATGD 34

treatment, including treatment likely to render a person infertile, experimental treatment, termination of pregnancy, or aversive stimulus, where

- 1) the treatment is the only or most appropriate way of treating the person
- 2) other treatment options have been pursued and been unsuccessful, or are not likely to promote the person's health and wellbeing, and
- 3) in the case of new treatment that has not gained the support of a substantial number of practitioners in the area, any relevant National Health and Medical Research Council guidelines have been complied with.

#### Case Study - Jane

Jane's guardian, her mother Kathy, came to Legal Aid NSW for advice. Jane is a young woman with a severe intellectual disability who experiences severe dysmenorrhoea, including pain and heavy bleeding. Various treatments have been tried, including pain medication and hormonal treatment, with limited success. Kathy had also experienced severe dysmenorrhoea and, after trying several different medical treatments, had a hysterectomy, which relieved her symptoms and dramatically improved the quality of her life. Kathy would like Jane to have access to the same treatment. We advised that under the current provisions of the *Guardianship Act*, it would be difficult to persuade the Tribunal to consent to a hysterectomy for Jane.

#### Q4.9 Supported decision-making for medical and dental treatment decisions

Legal Aid NSW considers that, wherever possible, informal supported decision-making arrangements should be respected. As noted in our submission to Question Paper 2, it is not clear that there is a need to formalise these arrangements. Instead, the approach in section 68(h) of the *Mental Health Act 2007* (NSW) should be adopted in all medical and dental treatment environments—that is, every effort should be made to involve the patient in the development of treatment and recovery plans and to consider their views and expressed wishes. This should include respecting the wishes of a person to have their supporter involved in discussions with practitioners and in decision making.

#### Q4.10 Consent for sterilisation

The current position, where only the Tribunal may consent to sterilisation, should be maintained. Legal Aid NSW considers that the changes proposed at Question 4.1 are consistent with the *Protocol for Special Medical Procedures (Sterilisation)* (Protocol). In particular, sterilisation would not be considered 'the most appropriate treatment' for the person if there is a less intrusive or permanent form of treatment available, or if the person has expressly objected to the procedure. The *Guardianship Act* already requires the views of persons subject to guardianship to be taken into consideration in the exercise of functions under the Act.<sup>5</sup> To remove any doubt, the Act could provide that the Tribunal

<sup>&</sup>lt;sup>5</sup> Guardianship Act s 4

must not consent to special treatment if the person has expressed an objection to the procedure, unless it is necessary to save the person's life or prevent serious damage to their health.

#### Q4.11 Preconditions for consent to sterilisation

As noted above, the Tribunal should be able to consent to sterilisation when that is the most appropriate form of treatment for the person and other treatments have been tried or are unlikely to be effective. It should be able to consent to sterilisation over the person's objection only where necessary to save the person's life or prevent serious damage to the person's health.

Q4.12 Matters that should not be taken into account

The Tribunal should not take into account

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

#### Q4.13-17 Advance care directives

Legal Aid NSW supports statutory recognition of advance care directives. We have no view as to whether such recognition should be in the *Guardianship Act* or in a standalone statute. There should be a requirement that the directive be in writing, signed and witnessed, so that, if necessary, the witness can provide evidence as to the capacity of the person and whether the directive was made voluntarily. However requiring the directive to be in an approved form or to be accompanied by a doctor's certificate could create barriers for people wishing to make advance care directives. In NSW, it is not necessary for advance care directives to include instructions about matters other than health care, or to include appointments of substitute decision makers, as enduring guardianship appointments are available for this purpose.

## Ch 5 Clinical trials

Generally, Legal Aid NSW considers that decision makers should only be able to consent to a person's participation in a clinical trial if that participation is for the purpose of promoting the person's health and wellbeing. The decision maker should take into account the views of the person, particularly their objection to participation, in making this decision. The current provisions in sub-sections 46(3) and (4) of the *Guardianship Act* are suitable in that they allow a guardian to consent to participation, despite the person's objection, only where that objection is a result of minimal understanding of the procedure and where participation in the procedure will result in only tolerable and transitory distress. In other circumstances, the consent of the Tribunal should be sought.

# Ch 6 The Guardianship Act and mental health legislation

Q6.1 The relationship between the Guardianship Act and the Mental Health Act

We refer to our preliminary submission, which noted that while the statutes appear to be clear that the *Mental Health Act* is the relevant statute regarding admission and discharge from a mental health facility, the case of *White v The Local Area Health Authority*<sup>6</sup> has cast doubt on the situation. Legal Aid NSW would support an amendment to make clear that the provisions of the *Mental Health Act* should have priority in this context. Similarly, the law should be amended to make clear that the involuntary administration of psychiatric treatment in the community should only occur as provided by the *Mental Health Act*, and not in reliance on the guardian's consent to medical treatment.

Q6.2 The relationship between the Guardianship Act and the Forensic Provisions Act

In our response to QP1, Legal Aid NSW noted concerns about the decision in *ERC*<sup>7</sup> where the Tribunal cast doubt on the utility of making a guardianship order in relation to a forensic patient subject to a detailed order under the *Mental Health (Forensic Provisions) Act* ('the MHFPA'). We consider that such an order can have utility. Firstly, we highlight that while the Mental Health Review Tribunal may order a forensic patient to live in a particular place or area, the Tribunal cannot negotiate with an accommodation provider or agree with a lessor. It may therefore be necessary to appoint a guardian to carry out practical steps in day to day decision-making.

Secondly, we highlight the role that a guardianship order can play as a transitional measure for forensic patients. A guardianship order can help manage any risk that a forensic patient poses and support their transition into the community. They provide a "less restrictive measure" that can be considered instead of extending a patient's forensic status. If less restrictive measures such as a guardianship order are not put in place, the Supreme Court may have no option other than to extend the patient's limiting term. This occurred in the case of *Attorney General v HRM*, where the Supreme Court considered an application to extend the limiting term of a sex offender with an intellectual disability. NCAT had adjourned an application for a guardianship order until the proceedings for the extension of the man's limiting term under the MHFPA had been heard. The Court therefore could not be satisfied that a less restrictive regime was available. It commented:

... it does seem that the learned members of NCAT have hesitation about making orders in a case where the Supreme Court has made orders under schedule 1 of the Act and the person is subject to ongoing supervision by the Mental Health Review Tribunal. Whether or not that is a correct view of the availability, or utility,

<sup>7</sup> [2015] NSWCATGD 14

<sup>&</sup>lt;sup>6</sup> [2015]

<sup>&</sup>lt;sup>8</sup> See Attorney General v HRM [2016] NSWSC 1189 at paras 23 and 27.

of guardianship orders, of course, is a matter which in the first instance will fall for decision by NCAT.

However, it does seem to me that the difficulty in this case – approaching the level of catch-22 – is that given the virtually unanimous opinion of the experts that HRM does need help and support to manage the risk that he does present to the community, this Court cannot be satisfied in the absence of an alternative less restrictive regime already in place that the application at hand should be dismissed.<sup>9</sup>

To help address the above issue, Legal Aid NSW recommends that the *Guardianship Act* be amended to expressly state that a guardianship order may be made in respect of a forensic patient as defined under section 42 of the MHFPA. As with the *Mental Health Act*, the *Guardianship Act* could state that a guardianship order is effective only to the extent that the terms of the order are consistent with any determination or order made under the MHFPA in respect of the patient. This would ensure that the guardianship order complements rather than replaces orders under the MHFPA.

## Ch 7 Restrictive practices

Legal Aid NSW considers that restrictive practices have a role to play in supporting forensic patients who are released from detention during or at the end of a limiting term. Forensic patients cannot be released unless the Mental Health Review Tribunal is satisfied that the safety of the patient or any member of the public will not be seriously endangered by the patient's release. <sup>10</sup> Legal Aid NSW supports the use of guardianship and restrictive practices for the benefit of the patient, where the practices will contribute to avoiding reoffending and further imprisonment. In this context, the use of restrictive practices should require a specific direction from the Guardianship Division of the Tribunal.

<sup>&</sup>lt;sup>9</sup> At paras 23-24.

<sup>&</sup>lt;sup>10</sup> Mental Health (Forensic Provisions) Act 1990 s 43(a)