

**Submission to the Law Reform Commission regarding the Review of the
Guardianship Act 1987, Question Paper 5:**

“Medical & Dental Treatment & Restrictive Practices”

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This submission specifically relates to the Section of the Guardianship Act 1987 that states that permission can only be given for “Special Medical Treatment – Hysterectomy or Endometrial Ablation” if the woman is unable to give informed consent & it is believed that the treatment is **“necessary to save the person’s life or prevent serious damage to their health”** (in addition to the Tribunal being satisfied that this treatment is **“the most appropriate form of treatment to promote the person’s health & wellbeing”**). Clearly, if the woman is able to give informed consent, obtaining permission for Special Medical Treatment from the Guardianship Tribunal would not be relevant.

The ability of women with intellectual disability (ID) to cope with menstruation depends to a large degree on the severity of the ID:-

- **Mild ID:** Usually can cope (and usually would be able to give informed consent for a hysterectomy if there were a medical indication).
- **Moderate ID:** May or may not be able to cope.
- **Severe ID:** Usually cannot cope.
- **Profound ID:** Invariably cannot cope but generally have 24 hour care and menstruation is managed by parents/carers with pads etc.

It is generally the women with moderate or severe ID who may have major problems related to menstruation, leading to “serious damage to health”. It is these two groups of women to which this submission particularly refers.

A number of such disabled women become extremely distressed during menstruation, have significant psychological problems at the sight of blood and are

unable to independently cope with menstrual pads or tampons. Clothes can be soiled with blood, behavioural difficulties can become more prominent & medical problems such as recurrent seizures can be exacerbated. Some of these women are unable to attend supported employment (Sheltered Workshops) or attend respite weekends or camps or overnight stays during menstruation. I am aware of a number of instances where an intellectually disabled woman has remained in the bathroom at her supported employment with blood over her clothes, due to the onset of menstruation. Consequently, there can be a significant reduction in the quality of life and serious damage to the person's mental or psychological health. To a lesser extent, there can also be serious damage to physical health due to infections associated with blood stained pads or tampons being unchanged for many hours (eg "toxic shock" syndrome).

I submit that the Guardianship Act should state that the Guardianship Tribunal should take particular account of the observations & comments of those closest to the woman with ID (such as parents, carers, work supervisors), in addition to relevant medical practitioners, while determining whether or not there has been or is likely to be serious damage to health.

In some situations where menstruation is causing severe damage to health, "the most appropriate form of treatment to promote the person's health & wellbeing" may be hormonal therapy. Examples include Depot Provera (which lowers oestrogen levels & thus increases the risk of osteoporosis & fractures, especially if used for 30-40 years until menopause) & continuous oral contraceptive tablets (which increase the risk of breast cancer & deep venous thromboses). Others such as intra-uterine devices (which frequently are not recommended in nulliparous women) & Implanon do not give a 100% guarantee of cessation of menstrual bleeding. However, for many women in these situations, some medical practitioners would consider it unethical to prescribe hormonal therapy for 30-40 years (in view of potential side-effects), particularly when alternative treatments are available (such as hysterectomy).

Currently, it is frequently very difficult for a young woman with moderate-severe or severe ID to obtain permission from the Guardianship Tribunal for a hysterectomy or endometrial ablation. The Act does not clarify that "damage to their health" refers to both mental/psychological health & physical health. Support for the fact that obtaining permission for a hysterectomy or endometrial ablation is difficult comes from a paper entitled "The Sterilisation of Girls & Young Women with Intellectual Disabilities in Australia: An Audit of Family Court & Guardianship Cases between 1992-

1998” by Susan M Brady, presented at the International Conference on Disability with Attitude: Critical Issues 20 years after the International Year of Disabled Persons (held at the University of Western Sydney in February 2001). This paper indicated that the Family Court approved 17 out of 19 applications while the Guardianship tribunals approved 10 out of 19 applications for sterilization, including hysterectomy, over the 7 year period. Although these numbers suggest that there were very few requests Australia-wide for “Special Medical Treatment”, it is well known in intellectual disability circles that many parents do not apply for permission from Guardianship tribunals when they believe an intervention such as a hysterectomy would markedly increase their daughter’s quality of life & mental health because (a) they believe there is “little chance” of success, & (b) they state they could not cope with the psychological trauma if the application were rejected.

In its decision in *Re Eve*, the Supreme Court of Canada defined a “therapeutic procedure” as “a surgical operation that is necessary for the health of the person” & indicated that, by health, the court meant “mental as well as physical health”. I submit that, in this review of the Guardianship Act 1987, the NSW Law Reform Commission should endorse this position.

I believe that most people would agree that, in general, all women have the right to parenthood. This view is stated in, amongst other documents, the UN Convention on the Rights of Persons with Disabilities & by the NSW Disability Inclusion Act 2014. A hysterectomy (& perhaps to a lesser extent, endometrial ablation) will render a woman sterile but both the Convention & the Act mentioned above state that if this Special Medical Treatment is necessary to save the person’s life or to prevent serious damage to health, it would be appropriate to recommend this intervention.

The other Australian States & Territories have legislated that treatment such as a hysterectomy to overcome “problems” with menstruation can only be undertaken in women with ID who cannot give informed consent provided the treatment is to save the person’s life or if it is deemed to be “in the person’s best interests”. South Australia includes “the only practicable way of dealing with the menstrual issues”. I submit that in this review of the Guardianship Act 1987, the NSW Law Reform Commission should consider, in the section relating to Special Medical Treatment, including reference to compassionate decisions that are “in the person’s best interests” so that serious damage to health is minimised. The Australian High Court’s decision in “Marion’s Case” (259-260) also referred to “....in the child’s best interests”.

I am aware that the Senate's Community Affairs Reference Committee report entitled "Involuntary or Coerced Sterilisation of People with Disabilities in Australia" (July 2013), in Recommendation 11 (in 5.126), recommended that all jurisdictions adopt "best protection of rights" tests to replace the current "best interests" tests. This Report was not primarily looking at the question of "Special Medical Treatment" & my submission is in no way reducing a person's rights. On the contrary, it enhances rights, as detailed in the NSW Disability Services Act 1993 & the NSW Disability Inclusion Act 2014, such as:

- (a) Have the right to realize their individual capacity for physical, social, emotional & intellectual development, &
- (b) Have the same right as other members of Australian society to services which will support their attaining a reasonable quality of life.

In conclusion, this submission to the NSW Law Reform Commission has been made in an attempt to change the section of the Guardianship Act 1987 that relates to "Special Medical Treatment – Hysterectomy or Endometrial Ablation". It is aimed at improving the quality of life & preventing serious damage to health (both mental & physical health) in women with moderate-severe or severe ID. This will be achieved if the alterations to the section result in increased chances of this relatively small number of women being granted permission to undertake the Special Medical Treatment.