

SUBMISSION TEMPLATE

THE NON-THERAPEUTIC STERILISATION OF MINORS WITH A DECISION-MAKING DISABILITY

Office of the Public Advocate, Victoria 26 May 2003

1. Should the proposed uniform decision-making principles set out in the Issues Paper be based on the Australian Guardianship and Administration Committee principles?

Yes

2. Should decision-making principles be set out in the Bill or the Guidelines?

As the decisions-making principles are extremely important and are unlikely to change over time, we believe they should be set out in the Bill.

3. Should guiding principles such as those set out on page 5 of the AGAC Protocol be included in the Bill?

Again we support the inclusion of guiding principles in the Bill. This is consistent with the adult guardianship legislation and emphasises the importance of the values on which the legislation is based.

4. With respect to who can make an application in relation to the non-therapeutic sterilisation of a minor;
 - a. should the Bill provide that one or both parents of the child or another person who can demonstrate that they have a 'sufficient' or 'proper' interest in the matter be able to make an application to the board or tribunal in respect of a minor with a decision-making disability?

OPA supports this option.

- b. Should there be any other criteria identifying who may make an application under the model Bill?

OPA cannot identify any situations which would not be covered by (a).

5. With respect to the definition of "child" and "minor", which of the options outlined in the Discussion Paper is the most appropriate? Would another proposal be more appropriate?

The Public Advocate considers that the legislation should be age based and apply to all persons under the age of 18. No disabilities should be specified as a person under the age of 18 has, by definition a legal decision-making incapacity

based on their age. We are aware of the Gillick principle which suggests that a greater degree of decision-making responsibility should be transferred to a young person as s/he moves towards maturity. However, the seriousness of a decision to sterilise a person, and the reality that the overwhelming majority of these procedures are performed on minors with a disability, either a cognitive or a profound physical disability, justifies reserving these decisions in all cases for the Tribunal or Court. This would not prevent the Tribunal making a decision about what level of involvement the minor should have in the decision-making process when hearing the application.

On balance, OPA would support the Guardianship Tribunal dealing with all applications for minors with a disability (cognitive and/or physical) and for the Family Court dealing with applications for those without a disability. This solution would prevent "forum shopping", raised as an issue in the discussion paper.

6. With respect to the definition of "non-therapeutic sterilisation", which of the options outlined in the Issues Paper is the most appropriate?

The Public Advocate favours Option 1, which defines sterilisation in terms of the result rather than the procedure.

"any treatment that is intended or is reasonably likely to have the effect of rendering permanently infertile the person on whom it is carried out"

We favour the removal of the term "non-therapeutic" from discussion/debate and legislation. If the legislation covers only "non-therapeutic" sterilisation, a medical judgment would be made prior to bringing the application as to whether the procedure is for therapeutic purposes. Guardianship legislation in Victoria requires all applications for sterilisation of adults to be authorised by the Guardianship Tribunal. The experience of OPA in relation to adults is that all applications for sterilisation are framed at least partly in therapeutic terms, the most common condition quoted being dysmenorrhea. Whilst there is dispute about the number of minors who have been sterilised over the past ten years (somewhere between 200 and 1200), there is no dispute that the number of sterilisation procedures approved by the Family Court is only a fraction of the total. It is therefore presumed that the rest were justified on therapeutic grounds.

If Option 1 is adopted and, as set out in the Issues Paper at the foot of page 13, some treatments were to be exempted, then care needs to be taken not to allow exemptions to be claimed too easily. For example, the Tasmanian exemption that is quoted could allow a doctor to claim the exemption on the grounds that menstruation was causing "significant distress".

There must, of course, be provision for emergency procedures to be performed which are necessary to save the life of a minor. OPA considers that the legislative provisions allowing a procedure to be carried out without consent to save a person's life or prevent serious damage to their health (if this is likely to occur within 48 hours) provides adequately for such situations. We consider the

example given in Option 2 (exempting medical treatment from which permanent infertility is an unwanted consequence) to be open to the same misinterpretation in practice as the therapeutic/non-therapeutic distinction.

Decisions about sterilisation procedures for children are particularly serious as they need to take account of whether maturation will affect the person's views and decision-making capacity, of possible changes in circumstances (for example a person moving out of the family home when they reach adulthood), of possible changes in the level of disability (for example the impact of mental illness) and most importantly the serious medical consequences of early sterilisation which are frequently underestimated (for example a greater incidence of osteoporosis and heart disease).

A benefit of having applications heard by the Guardianship Tribunal is that matters can be heard and a decision made, when necessary, within a very short time and certainly within a few days.

7. In relation to the decision-making 'tests' set out in the Issues Paper;
- a) Which test, if any, is the most appropriate?

The Public Advocate considers Option 1 - the "but for" test to be clearly the most suitable test for these serious decisions. It is consistent with the strong OPA view that people with disabilities have the same rights to bodily integrity and personal dignity as every other person and that these matters should not be decided on different criteria from those which apply to the rest of the community.

- b) Should more than one of the 'tests' set out in the Issues Paper be used? For example, should the last resort test be used with the best interests test as the over-riding principle?

No.

- c) Should the decision-making test/s be set out in detail? If so, should the test/s be set out/stated in the legislation or Guidelines?

We would support the decision-making test being set down in detail within the guidelines. This allows for some flexibility as thinking and experience develops in this area.

8. Should the model Bill or Guidelines deal with procedural matters, such as those outlined in the Issues Paper, or should these matters be left to individual jurisdictions?

Yes. OPA considers that these matters should be set down in the Bill or guidelines. These issues are so important that they should be heard by a three member Tribunal or Court with one member being a senior legal member and one member having appropriate medical expertise, either as a gynaecologist or a pediatrician.

9. Should the model Bill or Guidelines set out a statement of principle in relation to procedural matters? For example, a statement that the board or tribunal must be able to access any information relevant to making an informed decision?

Yes

10. In relation to the powers of inquiry of the Board or Tribunal:
- a. Should the model Bill contain a provision empowering the board or tribunal to order an investigation in sterilisation matters?

The Bill should contain a provision enabling the Tribunal to order an investigation in sterilisation matters. It is important that the Tribunal has before it all the information and/or advice it requires in order to make its decision at the hearing. Adjournments to gather further information or reports are extremely stressful to the person with a disability and, indeed, to all the parties in these sensitive matters. It is therefore important to conduct this investigation prior to the hearing.

- b. If so, who should carry out the investigation? For example, should it be the Office of the Public Advocate or Public Guardian?

OPA has experience in conducting these investigations and considers that it is the most appropriate organisation to conduct the investigations based on its statutory authority and independence, its experience and its value base which is underpinned by the principles of the *Guardianship and Administration Act 1986*

- c. What would be the resourcing implications of such a provision?

There would not be significant cost implications in Victoria as OPA already provides an investigation or advocacy report in all applications for sterilisation in the Guardianship Tribunal and the Family Court.

11. In relation to the medical evidence requirements discussed in the Issues Paper;
- a) Should these criteria be contained in the Bill or in the Guidelines?

These should be set out in the Bill.

- b) Is complete uniformity required on the issue of evidence or would it be more appropriate to allow each jurisdiction to develop its own provisions in this regard?

Whilst complete uniformity is not necessary, detailed guidelines should be developed.

12. In relation to the discussion in the Issues Paper about the need for a child's representative:
- a. Is it necessary for States and Territories to have uniform provisions?

Again OPA does not consider that there is a necessity for uniform provisions.

- b. If so, should the Bill require a child's representative to be appointed in sterilisation cases?

The issue of a child's representative should be decided on a case by case basis

- c. Alternatively, or additionally, should the Bill require that an advocate or advisor from the Office of the Public Advocate, the board or tribunal or other relevant organisation assess on a case-by-case basis whether the child needs separate representation?

See answer to (b)

- d. What resource implications would these requirements have?

OPA is of the view that where it is determined that a child's representative should be appointed that this should be provided by Legal Aid free of charge to the child or her/his parents. Again, the number of applications at present is very small so the resource implications would not be significant in comparison, for example, with child protection applications.

- 13. In relation to sanctions relating to the performance of an unauthorised sterilisation:
 - a) Should the model Bill contain a criminal offence for unauthorised sterilisation?

The model Bill should contain a criminal offence for unauthorised sterilisations, in keeping with the seriousness of the issue.

- b) If so, should the nature of the offence and/or penalties be uniform?

Yes, the nature of the offence and penalties should be uniform

- c) Who should be capable of being liable?

Liability should rest with the hospital and members of the hospital board, the treating physician, the surgeon and any person who purports to provide consent to the procedure.

- 14. Are there any additional matters which should be raised in this paper or addressed in the model Bill or Guidelines?

OPA considers that there should be consistency between legislation for adults and children. We note that this Bill relates only to sterilisations. Both guardianship legislation and the Family Court specify other and different Special Procedures. In Victoria, guardianship legislation defines special procedures as sterilisations,

termination of pregnancy, medical research and donation of non-regenerative tissue. The Family Court has defined special medical procedures as those involving difficult ethical issues, irreversible procedures, life threatening situations, treatments of significant risk and disputed treatments.

OPA considers that the Bill should also cover the donation of non-regenerative tissue by a child and situations where parents are not consenting to recommended treatment or are in dispute with each other about recommended treatment. Consideration should also be given to whether termination of pregnancy for a minor who has a disability should be covered to provide consistency with the guardianship legislation for adults and to provide protection for minors in these circumstances.

OPA suggests that SCAG consider whether the roles of the Guardianship Tribunal and the Family Court should be differentiated. One possibility mentioned above is for the Guardianship tribunal to deal only with children with disabilities and for the Family Court to deal with children without disabilities. The other possibility would be for the Family Court to be the Court of Appeal from the Guardianship Tribunal rather than the Supreme Court as is currently the case in Victoria in guardianship matters.