



Office of the Public Advocate

Further Submission to The Senate Standing Committee on Community Affairs References Committee

Inquiry into the involuntary or coerced sterilisation
of people with disabilities in Australia

Current practices and policies relating to the involuntary or
coerced sterilisation of intersex people

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1. About the Office of the Public Advocate

- 1.1. The Office of the Public Advocate (OPA) is a statutory office, independent of government and government services, which works to protect and promote the rights, interests and dignity of people with disabilities. OPA provides a number of services to work towards these goals, including the provision of advocacy, investigation and guardianship services to people with cognitive impairments or mental illnesses. In the 2012 financial year, OPA was involved in 1,708 guardianship matters, 531 investigations and 499 cases requiring advocacy or legal advocacy.

2. Summary of Recommendations

1. Intersex individuals should not be automatically assigned a gender at birth, or soon after. They should have as much time as they need to work out their own gender: female; intersex; or male. Assigning gender before they have begun to grow and develop as an individual does not necessarily advance an intersex child's human rights.
2. The term 'intersex medical intervention' should be used when a medical technology is used to intentionally alter an individual's physical or biological features so these more closely align with certain attributes of a particular gender.
3. Court authorisation is already (or ought to be) required whenever the performance of an intersex medical intervention upon a child is being proposed.
4. The perceived reversibility or irreversibility of medical interventions (or whether they are considered therapeutic or non-therapeutic) should not be a relevant factor for determining whether court authorisation is required.
5. Existing state administrative tribunal systems should be given concurrent jurisdiction with the Family Court to determine authorisation for intersex medical interventions proposed for a child.
6. An interdepartmental committee should be established by the Commonwealth Department of Health in cooperation with the Attorney-General's department called the Medical Interventions and Human Rights Advisory Committee (MIHRAC). This committee should sponsor the development of uniform intersex-status provisions for administrative tribunal jurisdiction across the states and territories, building upon current expertise and capacities.
7. The application to the administrative tribunal for intersex medical intervention applications would be without cost and its proceedings inquisitorial.



3. Intersex status and medical technologies

- 3.1. OPA understand intersex status as an issue of biological variability, reflecting the diversity of the human family. Intersex status involves a person having physical, hormonal or genetic features that vary from those of more common male or female persons.
- 3.2. A person of intersex status may identify as having one of the two more frequently occurring genders or they might identify as being of an alternative gender status. This identification may change over their lifetime.
- 3.3. In this submission we are concerned with the difficult ethical, social, political and legal issues raised by the use of medical technologies to address intersex status in some active way.
- 3.4. The term 'special [medical] procedure' is used in guardianship jurisdictions to distinguish medical interventions performed upon adults with cognitive impairment who are unable to give consent and which lie outside the scope of typical substituted decision-making arrangements.
- 3.5. The relevant provisions of the Victorian *Guardianship and Administration Act 1986* are attached at Appendix One.
- 3.6. The term is also used more broadly following the 1992 High Court *Marion* decision in *parens patriae* proceedings relating to children, which are heard in the Family Court of Australia.
- 3.7. Under a protocol with the Family Court, OPA is advised of Family Court applications when Court approval is sought for medical procedures involving children in Victoria, in particular 'children with an intellectual disability'. Over the past twenty-five years, OPA has been occasionally involved in such proceedings as an *amicus curiae*, and sometimes even as a party, in such cases (for a recent instance, see the case of Baby D 2011). In the last five years, these cases have not involved sterilisation applications.
- 3.8. An understanding of the current ethical framework for the medical profession in relation to intersex status has been set out in a guide published by the Victorian Government Department of Health, '*Decision-making principles for the care of infants, children and adolescents with intersex conditions*, February 2013.¹
- 3.9. On page four of the department's *February 2013* publication a subset of principles are set out which are concerned with achieving international best practice in hospitals, with reference to the *Consensus statement on management of intersex disorders*.
- 3.10. This particular sub-set of principles is concerned with *gender assignment*, that is, labelling a newborn individual as either being male or female. The key underlying principle of this subset is that all individuals should receive a gender assignment.
- 3.11. While it may be in the interests of the parents to have gender assigned to their newborn child this is not necessarily in the best interest of the developing individual.



- 3.12. It is our position that the intersex individual should have as much time as they need to work out their own gender: female; intersex; or male. While the United Nations Convention on the Rights of the Child obliges states to ensure children have a name and nationality it does not necessarily advance a child's human rights by assigning a gender before they have begun to grow and develop as an individual.
(Recommendation One)
- 3.13. Promoting the best interests of the child may mean deferring a settled (or transitory) gender status, although this might be uncomfortable for parents and many of our institutions.
- 3.14. There will need to be a readjustment in societal and medical thinking that there are only female persons and male persons. This linguistic and social simplification of gender status is out of step with what is now recognised as a more complex reality occurring in nature.
- 3.15. In the rest of this submission, we address those medical interventions which are intended to alter the individual's appearance and biological functioning so these more closely align with conceptions of certain typical attributes of either male persons or female persons.
- 3.16. We use the term 'medical intervention' for these kinds of procedures, in contrast with medical treatment. We also prefer to use the umbrella term 'medical technologies' rather than the term 'medical procedures'. (Recommendation Two)
- 3.17. Our preferred terms highlight that the practices we are considering are formed by the application of specialised branches of medical knowledge to address human problems in practical seeming ways, according to the assumptions and processes of those medical knowledge and practice systems. These specialised knowledge systems are limited in various ways. The term 'medical procedure' underplays the complex processes going on behind the performance of a knowledge-based practice that might be contested from other domains of knowledge.
- 3.18. The ethical principles for determining the best interest of the intersex child set out in the department's *February 2013* publication on page five include minimizing physical and psychosocial risks to the child; leaving open options for the future; and preserving fertility and the capacity for satisfying sexual relations.²
- 3.19. OPA supports these ethical principles.
- 3.20. The publication also discusses legal principles on page six and sets out the following 'four threshold questions' for determining whether court authorisation is required for a proposed medical intervention³
- The proposed treatment is non-therapeutic
 - ... is invasive, irreversible and considered 'major' treatment
 - There is a significant risk of making the wrong decision about the best interests of the child
 - The consequences of a wrong decision are particularly grave.



- 3.21. OPA accepts that these principles give adequate general guidance on the current law on these matters.
- 3.22. The inescapable implication for all intersex medical interventions of these ethical requirements for determining the child's best interests in combination with these accepted legal principles is that authorisation is always a matter for determination by the court system and its tribunals.
- 3.23. To be clear, it is OPA's firm view that court authorisation is already (or ought to be) required whenever the performance of a medical intervention upon a child is being proposed for the purpose of altering the individual's appearance and biological functioning so these more closely align with conceptions of certain typical characteristics of either male persons or female persons. (Recommendation Three)
- 3.24. We further believe that this interpretation should be clarified as soon as possible through law reform so that the human rights of intersex-status persons are properly safeguarded.
- 3.25. While the Family Court of Australia does have current jurisdiction on these matters for persons under eighteen-years old, state administrative tribunal systems should be given concurrent jurisdiction with the Family Court to determine authorisation for intersex medical interventions proposed for a child in a more accessible way. This issue is discussed further below.
- 3.26. OPA understands that one of the complications in allocating responsibility for decision-making is the crossover of medical interventions with less contentious medical treatment proposed for medical conditions. We believe the point of distinction lies in the intention behind the medical treatment or intervention. In this schema, medical technologies initiated to address childhood gender-identity disorder are medical interventions, rather than medical treatment.
- 3.27. OPA does recognise that this distinction may not always be clear-cut. It does raise issues analogous to the blurring of distinction between 'non-therapeutic' and 'therapeutic' sterilisations that we raised in our previous submission.⁴ Recognising that this may occur, we still believe it is possible to make such a distinction between intersex medical interventions and medical treatment, superseding the former distinction that has developed in case law originally conceptualised around therapeutic benefit for an unhealthy body.
- 3.28. We make this distinction because it is our position, as stated above, that any intersex medical intervention performed upon a child must only proceed with the consent of our courts or tribunals.
- 3.29. We base our position on a number of elements. A key reason is our understanding of the implications of the social model of disability. It is usually highly inappropriate to perform corrections upon the bodies of individuals when the problems actually lie elsewhere in social relations and other social factors.



- 3.30. We are very concerned about the social consequences of medical interventions for the individual, including the immediate or delayed risk of rejection by sections of the community and significant others.
- 3.31. We also note the lack of longitudinal studies about the long-term consequences of these medical interventions. We do not have reliable information about the experiences of people who have had these interventions performed upon them as young children. We do not know the proportion of people who are satisfied with the outcome or what proportion have ultimately regretted the intervention.
- 3.32. While OPA is unable to provide hard data, we understand that there has been increasing litigation pursuing a remedy for wrongful intersex medical interventions performed upon children in the USA and UK.
- 3.33. For intersex medical interventions to be truly scientifically based we need further evidence of their efficacy in the lives of individuals, beyond the more limited indicators of the initial success of the technological approach itself. The interventions are postulated as a practical way of bringing about a more desirable end-state for the individual, based on a set of assumptions about what works for intersex status individuals. We lack evidence of whether quality of life is actually improved in the long-term over the (young) patient's life course.
- 3.34. There is a further implication of our approach relating to the perceived reversibility or irreversibility of a medical intervention. We recognise that this distinction has been made in judicial interpretation of certain cases and forms part of the common law approach to these issues.
- 3.35. We suggest that the perceived reversibility or irreversibility of medical interventions (or whether they are considered therapeutic or non-therapeutic) should not be a relevant factor for determining whether court authorisation is required. (Recommendation Four)
- 3.36. We make this suggestion because the medical-technological approach inevitably involves putting in place a particular and limited way of understanding the patient's condition and its remedies. The assumptions, processes and expectations that are set in train once this trajectory is selected cannot be easily stopped or questioned. There are also problems with distinguishing categorically between reversible and irreversible interventions.
- 3.37. We also propose that it is not possible for a child to be *Gillick* competent in relation to intersex-status medical interventions. We believe that the courts and tribunals should always exercise the duty of determining authorisation for proposed interventions upon children.
- 3.38. Our reasoning is that the consequences of these medical interventions are so far reaching that a child with only an emerging or no experience of adulthood cannot know what they will want for themselves as a mature adult.
- 3.39. This position may seem to lack compassion for a young developing person who is developing their capacities and doing their best to understand and establish their own



deeply private and essential identity during times involving critical developmental milestones and confusing circumstances.

- 3.40. We note that the medical interventions proposed for childhood gender-identity disorder that have been termed pharmaco-therapeutic treatments do not treat the immediate diagnosis itself. These interventions instead modify an otherwise healthy body so as to align it with a desired identity state, while that self-identity is still unstable and forming.
- 3.41. The connection of some of these medical technologies with developmental processes creates a perceived urgency for assessing and deciding upon these interventions prematurely, that is, before the person can really know what it is that they want for themselves for the rest of their life. It is not possible for the child to make a fully informed decision because they lack critical self-knowledge. They also cannot make a good-enough informed decision because they are unable to rely on evidence drawn from the experience of others because it is not available.
- 3.42. We point to the human rights issues at stake here for the child. Under the United Nations *Convention on the Rights of the Child* (UNCRC) Australia has a duty to ensure the human rights of children up to eighteen years of age⁵.
- 3.43. Australia is obliged to take all possible appropriate legislative, administrative, social and educational measures to protect children, and to work towards what is best for the child. While the developing capacity of the child has to be respected and supported it is not appropriate to make a child the decision maker for such a complex issue before they become an adult under the law.

4. Existing and new legal arrangements

- 4.1. The Victorian Civil and Administrative Tribunal (VCAT) currently considers 'special [medical] procedures' as defined under Section 3 of the Guardianship and Administration Act 1986 .
- 4.2. Other guardianship jurisdictions have similar provisions, although these are not uniform across Australia.
- 4.3. VCAT is an accessible and inquisitorial forum which regularly hears cases involving the medical treatment of adults who by reason of disability lack the capacity to give consent to the treatment.
- 4.4. OPA strongly supports VCAT's authority that it already has in relation to adults with disability being extended to include intersex medical interventions.
- 4.5. OPA has previously recommended the extension of VCAT's jurisdiction in Part 4A of the *Guardianship and Administration Act* to include children, giving VCAT concurrent jurisdiction with the Family Court of Australia to hear sterilisation applications regarding minors.



- 4.6. With additional resources, this existing administrative tribunal approach could be used nationally in relation to an intersex medical intervention proposed for a child, sharing the jurisdiction of the Family Court. (Recommendation Five)
- 4.7. Tribunals will offer a number of advantages, analogous to the benefits that have been realised in relation to guardianship processes. This approach will enhance the rule of law because of the more accessible nature of the venue, and the increased capacity for an inquisitorial approach that tribunals can provide.
- 4.8. The relevant provisions of the Guardianship and Administration Act 1986 (Vic) (GAA) only currently apply for people aged 18 and over. These provisions regulate 'medical treatment' and 'special procedures'. The latter includes 'any procedure that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out'. (See Appendix One)
- 4.9. The GAA does not distinguish specifically between therapeutic and non-therapeutic treatment. VCAT may give consent if it determines it is the patient's best interests to do so (s.42E), according to specified criteria (s.38). VCAT must consider 'whether the treatment to be carried out is only to promote and maintain the health and well-being of the patient'.
- 4.10. The current functions and operations of VCAT were usefully summarised in Chapter 21 of the Victorian Law Reform Commission publication Guardianship Consultation Paper 10.⁶
- 4.11. We further note that the definition of medical treatment under the GAA is not consistent with definitions contained in other Victorian legislation. These sorts of issues will need to be addressed as new provisions are considered. An example of particular relevance is that under the guardianship act the administration of pharmaceuticals is not considered 'medical treatment'.
- 4.12. While there are some known problems with current GAA provisions it is OPA's position that these could provide a model for VCAT consideration of intersex status medical interventions, so that there was concurrent jurisdiction with the Family Court of Australia.
- 4.13. We are not advocating a particular approach or legislative provision because we believe there is a need for a cautious approach and further preparatory work, balanced with some urgency as these are significant human rights issues with far reaching consequences for many people.
- 4.14. Balancing this caution with urgency should be the responsibility of a 'special medical procedures' committee that can advise the government on how to best advance these issues and protect the human rights of intersex-status Australians.
- 4.15. This body should be an interdepartmental committee established by the Commonwealth Department of Health in cooperation with the Attorney-General's Department



- 4.16. This committee could be more properly termed the Medical Interventions and Human Rights Advisory Committee (MIHRAC)
- 4.17. MIHRAC should sponsor the development of uniform intersex-status provisions for administrative tribunal jurisdiction across the states and territories, building upon current capacities. (Recommendation Six)
- 4.18. Expertise and input could be sought from human rights bodies, the attorneys-general, and public advocates, public guardians and tribunal bodies coordinated through the Australian Guardianship and Administration Council (AGAC). This body has previously developed protocols around sterilisation, as discussed in our previous submission.⁷
- 4.19. VCAT usually asks OPA to investigate and report when there is an application before it for authorisation for a special procedure.
- 4.20. Under the *Victorian Civil and Administrative Tribunal Act 1998* it is already possible for VCAT to refer a matter for investigation and report to bodies other than OPA, including public authorities and service providers.
- 4.21. As stated above, OPA believes there are sound reasons for implementing a nationally consistent approach so that an application to a tribunal must be made for all medical interventions that will alter the biological and physical features of an intersex-status person.
- 4.22. In some limited circumstances, the application may prove to be uncontroversial and not result in a hearing.
- 4.23. OPA expects that for most applications the tribunals will need to fully consider and determine the best interests of the intersex person through a full hearing.
- 4.24. The tribunal should be inquisitorial so that it can be fully satisfied on the question of best interests. When considering authorisation the tribunal could weigh up all the questions relating to reversibility, therapeutic benefit, the wishes of the child and so forth, which will have some strong similarities with what they already do in relation to special procedures. Access to the tribunal for these applications should be without cost. (Recommendation Seven)
- 4.25. It is important to note that guardianship jurisdictions and administrative tribunals are already dealing with significant and growing workloads and reform processes. Additional resources will be required for the development and implementation of these further capabilities.
- 4.26. Other issues that may need to be considered include how appeals against tribunal decisions will be handled, and what relationship this might have with the Family Court jurisdiction. In Victoria, decisions of VCAT can only be appealed on a question of law to the Supreme Court of Victoria. If a Member of VCAT who is a Judge of the Supreme Court or County Court makes the decision, leave to appeal must be given by the Court of Appeal.⁸



5. Summary

- 5.1. Because these issues raise complex social and legal reform issues we are suggesting a cautious approach to resolving some of the complex issues raised by the application of medical technologies to the bodies of intersex people.
- 5.2. We also note that there must be some speedy action by legislators and experts to create a new statutory system to safeguard the human rights and well-being of intersex-status people who are potentially subject to medical interventions. The current approaches are not providing adequate protection and need to be reformed.
- 5.3. Balancing this caution with urgency should be the responsibility of a new interdepartmental committee, the Medical Interventions and Human Rights Advisory Committee, to advise the government on how to best advance these issues and protect the human rights of intersex-status Australians.
- 5.4. We have advanced seven recommendations that should be implemented to advance and safeguard the human rights of intersex persons.
- 5.5. OPA is happy to be contacted further about these issues and will explore how these issues might be considered within the Australian Guardianship and Administration Council.



6. Appendix One

Relevant provisions, *Guardianship and Administration Act 1986*

See: http://www.austlii.edu.au/au/legis/vic/consol_act/gaaa1986304/

s. 3 Definitions

special procedure means—

- (a) any procedure that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out; or
* * * * *
- (c) termination of pregnancy; or
- (d) any removal of tissue for the purposes of transplantation to another person; or
- (e) any other medical or dental treatment that is prescribed by the regulations to be a special procedure for the purposes of Part 4A;

s.36 Persons to whom Part (4A of the GAA) applies

(1) In this Part, patient means a person with a disability who—

- (a) is of or over the age of 18 years; and
- (b) is incapable of giving consent, within the meaning of sub-section (2), to the carrying out of a special procedure, a medical research procedure or medical or dental treatment, whether or not the person is a represented person.

(2) For the purposes of paragraph (b) of the definition of patient in sub-section (1), a person is incapable of giving consent to the carrying out of a special procedure, a medical research procedure or medical or dental treatment if the person—

- (a) is incapable of understanding the general nature and effect of the proposed procedure or treatment; or
- (b) is incapable of indicating whether or not he or she consents or does not consent to the carrying out of the proposed procedure or treatment.

s. 38 Best interests

(1) In this Part, for the purposes of determining whether any special procedure or any medical or dental treatment would be in the best interests of the patient, the following matters must be taken into account—

- (a) the wishes of the patient, so far as they can be ascertained; and
- (b) the wishes of any nearest relative or any other family members of the patient; and
- (c) the consequences to the patient if the treatment is not carried out; and
- (d) any alternative treatment available; and
- (e) the nature and degree of any significant risks associated with the treatment or any alternative treatment; and
- (f) whether the treatment to be carried out is only to promote and maintain the health and well-being of the patient; and
- (g) any other matters prescribed by the regulations.

s. 42A Emergency medical or dental treatment

(1) A registered practitioner may carry out, or supervise the carrying out of, a special procedure, a medical research procedure or medical or dental treatment on a patient without consent under this Part or authorisation under section 42T if the practitioner believes on reasonable grounds that the procedure or treatment is necessary, as a matter of urgency—

- (a) to save the patient's life; or
- (b) to prevent serious damage to the patient's health; or
- (c) in the case of a medical research procedure or medical or dental treatment, to prevent the patient from suffering or continuing to suffer significant pain or distress.



s. 42B Application for consent of Tribunal to special procedure

(1) An application for the consent of the Tribunal to the carrying out of any special procedure on a patient may be made by-

- (a) the person responsible for the patient; or
- (b) any person who, in the opinion of the Tribunal, has a special interest in the affairs of the patient.

...

(3) The Tribunal must give notice of an application, of the hearing of the application and of any order, directions or advisory opinion of the Tribunal in respect of the application to-

- (a) the Public Advocate

s. 42E Consent of Tribunal to special procedure

On hearing an application under this Division, the Tribunal may consent to the carrying out of a special procedure only if it is satisfied that—

- (a) the patient is incapable of giving consent; and
- (b) the patient is not likely to be capable, within a reasonable time, of giving consent; and
- (c) the special procedure would be in the patient's best interests.

s. 42G Special procedure without consent of Tribunal an offence

(1) Subject to section 42A, a registered practitioner must not carry out, or supervise the carrying out of, any special procedure on a patient unless—

- (a) the Tribunal has consented to the carrying out of that procedure; or
- (b) the person responsible with authority to consent to the continuation of the procedure or a further special procedure under section 42F has consented to the carrying out of that procedure.

Penalty: Imprisonment for 2 years or 240 penalty units or both.

(2) A registered practitioner who, in good faith, carries out, or supervises the carrying out of, a special procedure on a patient in the belief on reasonable grounds that the requirements of this Division have been complied with and in reliance on—

- (a) a consent given by another person whom the registered practitioner believed on reasonable grounds was authorised to give such consent; or
- (b) a purported consent given by another person whom the registered practitioner believed on reasonable grounds was authorised to give such consent but was not so authorised—is not—
- (c) guilty of assault or battery; or
- (d) guilty of professional misconduct; or
- (e) liable in any civil proceedings for assault or battery; or
- (f) guilty of an offence against sub-section (1).

(3) Nothing in this Division affects any duty of care owed by a registered practitioner to a patient.

7. Endnotes

¹ Victorian Government Department of Health, *Decision-making principles for the care of infants, children and adolescents with intersex conditions, February 2013*. (2013)

² Ibid

³ Ibid

⁴ Lesley Naik, 'When is the sterilisation of an intellectually disabled child "therapeutic"? A practical analysis of the legal requirement to seek court authorisation' (2012) 20 (453) *Journal of Law and Medicine* 453-63

⁵ United Nations General Assembly, *Convention on the Rights of the Child* (1989)

⁶ Victorian Law Reform Commission, *Guardianship Consultation Paper 10* (2011)

⁷ AGAC, Protocol for special medical procedures (sterilisation) (2009)

⁸ http://www.agac.org.au/images/stories/agac_sterilisation_protocol_30_mar_09.pdf, accessed 11 September 2013

⁸ <http://www.vcat.vic.gov.au/disputes/residential-tenancies/review-or-appeal-vcat-decision> accessed 11 September 2013