



Office of the Public Advocate

Submission to The Senate Standing Committee on Community Affairs References Committee

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

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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 last financial year, OPA was involved in 1,708 guardianship matters, 531 investigations and 499 cases requiring advocacy or legal advocacy.
- 1.2. OPA welcomes this further opportunity to submit to the Senate Community Affairs References Committee on a significant human rights matter: the sterilisation of people with disabilities.



2. Summary of Recommendations

1. OPA supports Commonwealth legislation to establish a uniform national framework for the sterilisation of minors, which fully safeguards their human rights and ensures that Australia is fully compliant with its international law obligations, even though we hold the view that the Family Court is not the ideal forum for the making of these decisions.
2. That in the absence of Commonwealth legislation, the Victorian State Government should establish concurrent jurisdiction for the Victorian Civil and Administrative Tribunal with the Family Court of Australia to hear sterilisation applications regarding minors.
3. That the primary health care professional bodies review the adequacy of the current guidance, training and specialist support available to practitioners, and that they ensure their members are fully equipped to recognise the presence of cognitive impairment, understand its implications for decision-making capacity, and provide professional services in conformance with contemporary legal and human-rights requirements.
4. That sexual health and family planning services target and give priority to providing effective counseling, education and related support to people with a cognitive impairment and their families.
5. That state and territory governments provide targeted resources to funded sexual health and family planning services that they acquit for by demonstrating continuing additional services to people with a cognitive impairment.
6. That state and territory governments provide financial assistance to appropriate non-government organisations to produce community education materials, and best-practice policy frameworks, which promote a positive message of the sexuality of people with disabilities, within a human rights framework.
7. That all specialist disability services providing support to children and adults with decision-making support needs ensure they are supporting maximal opportunities for their clients to explore friendships, social relationships and their own sexual identity and attraction in the ways typical of their peers who do not have an identified disability.



8. That within the present funding arrangements, state and territory governments ensure through quality assurance, service monitoring and funding arrangements that funded specialist disability services are required to support maximal opportunities for their clients to explore friendships, social relationships and their own sexual identity and attraction in the ways typical of their peers who do not have an identified disability.
9. That within the present funding arrangements, state and territory governments ensure families and individuals have continuing access to good information about disability service systems and support, at the earliest possible stage after the impact of disability is first recognised, from adequately funded disability information, referral and self-help services.
10. That relevant research-related bodies, such as the National Health and Medical Research Council, the Australasian Society for the Study of Intellectual Disability, and the Centre for Developmental Disability Health, explore how more research can be conducted on the sterilisation of people with disabilities and related topics.
11. That the Australian Institute of Health and Welfare, in partnership with other bodies, develops more detailed guidelines for the reporting of sterilisation procedures, which reliably distinguish between therapeutic and non-therapeutic procedures, to ensure as much consistency as possible in measurement and data collection, both within and between jurisdictions.
12. That the federal, state and territory governments ensure individuals with disabilities and their families have good access to independent advocacy, including legal advocacy, through a significant expansion in funding for this purpose. This advocacy support must focus on addressing the social and personal wellbeing of people with disabilities.
13. That state and territory governments enact legislation to make procuring or abetting the coercive sterilisation of people with disabilities without judicial authority a criminal offence, with serious penalties for conviction.
14. That the Australian Government ensures the design and operation of the National Disability Insurance Scheme accommodates the issues raised in this submission and its recommendations.



3. Background

- 3.1. In Victoria, the current legal requirements are quite different concerning:
- a) the sterilisation of children (those with and without disabilities), and
 - b) the sterilisation of adults who are unable to make their own medical treatment decisions.
- 3.2. The sterilisation of children (with disabilities) is a matter covered by the common law, following the 1992 High Court *Marion* decision. This decision requires Family Court approval before a child is sterilised unless sterilisation occurs because of an appropriate 'therapeutic' procedure carried out to address an actual health issue.
- 3.3. There is concern that within medical practice the distinction between 'non-therapeutic' and 'therapeutic' sterilisations has become blurred.¹
- 3.4. When parents and professionals are considering the sterilisation of a child, they should ask themselves whether they are only considering this procedure because of the child's disability (the 'but for' test). If this procedure would not be considered for a child without a disability then judicial authority has been obtained as it must be a non-therapeutic procedure that is being considered.²
- 3.5. OPA has been involved in medical cases involving children over the past twenty-five years.
- 3.6. 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'. OPA is occasionally involved 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. We are aware of one case which did not proceed to a Family Court application.
- 3.7. OPA has had longstanding concerns about the continuing sterilisation of children with disabilities.³ We recently stated our position in a statement of December 2011.⁴
- a) There is serious concern that the legal requirements set out in the Marion decision are not always being followed and that illegal sterilisations are being performed (that is, with parental approval only, not with Court approval).
 - b) This court application process is not ideal because it is expensive and adversarial, which act as significant disincentives for pursuing this process.

¹ 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

² Ibid

³ Natalie Tomas, *The reproductive rights of women with disabilities* (2004)

⁴ Office of the Public Advocate, 'OPA Position Statement on the Sterilisation of Children' (2011) available from <<http://www.publicadvocate.vic.gov.au/file/file/Research/Position%20statements/Sterilisation%20position%20statement%20December%202011.doc>>



- c) The Marion case itself highlighted the need for legislative reform to provide a more appropriate legal process for decision making.
- 3.8. The sterilisation of children in situations which are not life threatening usually amount to a serious violation of the rights and dignity of a child with disabilities. Commonwealth law needs to adequately address and prevent such occurrences, as the important issue at stake is the protection of the human rights of children, and especially girls and young women with disability, not the number of procedures performed.
- 3.9. We have advocated a number of reforms in relation to the continuing sterilisation of children with a disability. We have called for:
 - a) Commonwealth legislation on this matter.
 - b) In the absence of Commonwealth legislation, the creation of a shadow jurisdiction for the Victorian Civil and Administrative Tribunal (which has authority to make decisions in relation to the sterilisation of adults with cognitive impairments).

OPA Position on Proposed Commonwealth legislative reform

In the Marion decision, the High Court invited the legislature to consider reform, with four of the judges stating that:

[W]e acknowledge that it is too costly for most parents to fund court proceedings, that delay is likely to cause painful inconvenience and that the strictly adversarial process of the court is very often unsuitable for arriving at this kind of decision. These are clear indications of the need for legislative reform, since a more appropriate process for decision-making can only be introduced in that way.

This call produced a spate of discussion papers and law reform reports between the 1990s and early 2000s, which culminated in a decision by the Standing Committee of Attorneys-General (SCAG) to seek a uniform national framework for the sterilisation of minors. Although SCAG initially proposed to introduce national legislation regulating the sterilisation of minors, this was later abandoned. SCAG cited controversial evidence of the declining number of sterilisations as justification for its decision.

More recently, in January 2011, the United Nations Periodic Review of Australia was critical of Australia's position on sterilisation and called on Australia to abolish "non-therapeutic sterilisation of children", a call backed by Australia's Sex and Disability Discrimination Commissioners, Elizabeth Broderick and Graeme Innes.

OPA would welcome Commonwealth legislation on the sterilisation of minors, which enshrines Australia's international legal obligations to promote and protect the rights of minors with disabilities.

OPA supports Commonwealth legislation even though it holds the view that the Family Court is not the ideal forum for the making of these decisions.

Reasons why the Family Court is not the optimal forum include the:



- relatively small number of such cases that come before the Family Court
- uncertainty over when its authorisation is required
- adversarial nature of Family Court hearings
- high financial costs of Family Court applications

The latter two points are significant disincentives for the bringing of matters to the Family Court. This significantly weakens the ability of the Court to provide effective oversight of ethically complex medical treatment decisions concerning children.⁵

RECOMMENDATION

1. OPA supports Commonwealth legislation to establish a uniform national framework for the sterilisation of minors, which fully safeguards their human rights and ensures that Australia is fully compliant with its international law obligations, even though we hold the view that the Family Court is not the ideal forum for the making of these decisions.

- 3.10. In the absence of Commonwealth legislation, OPA calls for Victorian legislative reform.
- 3.11. Under the Guardianship and Administration Act 1986, the Victorian Civil and Administrative Tribunal (VCAT) can authorise “special procedures” to be performed on adults with disabilities, which includes sterilisation.
- 3.12. OPA calls for this authority to be extended so that VCAT is given concurrent jurisdiction with the Family Court of Australia to hear sterilisation applications regarding minors.
- 3.13. This would bring Victoria into line with other jurisdictions in Australia where tribunals have concurrent jurisdiction with the Family Court.
- 3.14. In Victoria, the recent Victorian Law Reform Commission (VLRC) report into the existing guardianship law for adults with impaired decision-making capacity did not recommend the extension of jurisdiction for minors to VCAT, although this suggestion was put to the VLRC by OPA.⁶
- 3.15. Apparently, the VLRC did not make this recommendation because of doubt over the validity of the proposed concurrent jurisdiction arrangement between VCAT and the Family Court.

⁵ Ibid

⁶ <http://www.lawreform.vic.gov.au/inquiries/guardianship>, accessed 3 January 2013



- 3.16. OPA does not accept this view and is continuing to raise this issue with the Victorian Government.

RECOMMENDATION

2. In the absence of Commonwealth legislation, the Victorian State Government should establish concurrent jurisdiction for the Victorian Civil and Administrative Tribunal with the Family Court of Australia to hear sterilisation applications regarding minors.

- 3.17. **In relation to the sterilisation of adults** who are unable to make their own medical treatment decisions, our position is that Victoria's legal process — which normally requires the approval of the Victorian Civil and Administrative Tribunal before a person with a cognitive impairment is able to undergo a sterilisation procedure — is mostly adequate.

- 3.18. Our remaining concerns about the Victorian VCAT process for adults are that we are not completely confident that this process is always being used properly.

- a) The extent to which this process is not being properly followed is unknown.
- b) The issue of determining when an adult does not have the capacity to make their own medical treatment decisions is often problematic, leading to the possibility that informed consent is sometimes being both assumed or denied inappropriately.

**Comment on the Guardianship and Administration Act 1986 and
Victorian Charter of Human Rights and Responsibilities**



The relevant provisions of the Guardianship and Administration Act 1986 (Vic) (GAA) only 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'.

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). Pertinently, a criterion is 'whether the treatment to be carried out is only to promote and maintain the health and well-being of the patient'.

OPA is asked to investigate and report when there is an application before VCAT for a special procedure. An OPA investigator explores whether the procedure is for therapeutic or non-therapeutic reasons, and how the best-interest criteria are being met. OPA also undertakes advocacy, directed towards resolving the matter less restrictively, when sterilisation is proposed for non-therapeutic reasons.

OPA files indicate there are around seven applications per year to VCAT concerning sterilisation of adults with cognitive impairments.

Both the Tribunal and OPA as 'public authorities' under the Charter of Human Rights and Responsibilities Act must act compatibly with the human rights of persons – and the right (s.10) not to be 'subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent'.

The fact of disability does not mean that the adult patient is incapable of making such a decision for herself or himself. If the treating doctor reasonably considers she or he is capable of consenting, then a substitute decision-maker is not required, nor is VCAT's approval required.

If the patient is deemed incapable then approval must be obtained from the tribunal if the procedure is a special procedure (or consent is required from the 'person responsible' in relation to other medical treatment). Such a decision should be informed by the criteria in s.38 (GAA) in determining whether treatment is in the patient's best interests.



4. Sterilisation practices, access to sexual health, and related services

- 4.1. In this section, OPA addresses the following term of reference: *(a) the types of sterilisation practices that are used, including treatments that prevent menstruation or reproduction, and exclusion or limitation of access to sexual health, contraceptive or family planning services.*
- 4.2. Parents and health provider's responses to the emergent and actual sexuality and adulthood of their child or client can be highly affected by historical, cultural and social tendencies that are harmful to people with disabilities, including eugenic thinking.
- a) With a variety of expressions, there is widespread social disapproval of women with intellectual disability having and parenting children..
 - b) There are good grounds for remaining concerned that there is continuing coercive sterilisation of women with disability, and active discouragement of their sexuality or childbearing.
 - c) In this broader social milieu, some parents are seeking sterilisation of their child for what superficially seem beneficent reasons.
 - d) The parents pursuing sterilisation of their child may be seeing it as the solution to the problem of her sexuality or her child-bearing capacity (fertility), although these are quite different issues.
 - e) Although for the parent the most important underlying issue may either be their child's sexuality or fertility they may sometimes express or understand this perceived problem in terms of her physical wellbeing, comfort or emotional condition.
 - f) Amongst other consequences, sterilisation can increase a growing child or adult's vulnerability if carers confuse fertility control with sexuality, and then deny her continuing needs for sex education and for protection from sexual exploitation and assault.
- 4.3. A two-year audit of women with cognitive impairments contacting a Melbourne hospital-based Pregnancy Advice Service reported in 2010 made the following relevant findings⁷ :
- a) The consequences of failing to acknowledge women with intellectual disability as sexual beings still results in many barriers.
 - b) Women with intellectual disability experience difficulty accessing health services, inadequate or inappropriate supports and a lack of accessible information.
 - c) The study findings indicate that support, education and contraceptive needs are not being adequately met with 45% of women in the study seeking assistance with an unplanned pregnancy at 12 weeks gestation or later, compared with 20% of the general population of women using the Pregnancy Advice Service. One quarter of the women recognised their pregnancy too late to obtain an

⁷ Burgen, Brenda (2010) Women with cognitive impairment and unplanned or unwanted pregnancy: a 2-year audit of women contacting the Pregnancy Advisory Service', Australian Social Work, 63:1, 18-34



abortion compared with only 2% of the general population of women using the service. Only half of the women had support from formal services, but in half of these cases the service involved was Child Protection. None of the twenty women in the study were living in disability supported accommodation services.

- d) The limited research available shows that adolescents and adults with intellectual disability have only very poor contraception and pregnancy related knowledge.
- 4.4. A 2009 UK study of 23 women found their knowledge of how contraception works was very limited. Approximately half the women also lacked basic knowledge about reproduction. None had been given any accessible information about contraception. All of the women were either former or current contraception users. The women all had relatively high levels of ability and social functioning. While this was a UK study it does point to a serious problem.⁸
- 4.5. An earlier study by this UK researcher found that of fifteen women using contraception only one seemed to be exercising her own choice and control.
- 4.6. US studies also suggest that little, if any, accessible information about contraception and sexual and reproductive health is given to people with intellectual disability, especially younger people. Teenagers with intellectual disability received less classroom instruction than their non-disabled peers. As well, fewer parents of children with intellectual disability discussed sex, pregnancy and sexually transmitted infections with their child.⁹
- 4.7. A part of the problem is that treating doctors and health services might not hear the voice of the girl or women with disabilities, or have the necessary competence to ascertain her wishes or determine her capacity.
- a) Doctors will be accustomed to hearing the child being spoken for by her parents whom have interests and values of their own to promote, such as managing a household with limited resources, or their own emotions, values and views concerning sexuality.
 - b) The parents may not be capable of or used to conceiving of their child as a rights-bearing minor or adult.
 - c) Doctors and paediatricians might not have received the necessary training or professional development to effectively communicate with the child, or to recognise her human rights and emerging adulthood and autonomy.
- 4.8. It is unacceptable to address social and service system issues through inappropriate medical interventions performed upon an individual's body.
- 4.9. Many of the points made above were raised in by a recent OPA investigation, which is presented as a case study below.

⁸ McCarthy, M. (2009), Contraception and Women with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22: 363–369. doi: 10.1111/j.1468-3148.2008.00464.x

⁹ Cheng, Marian Mantsun, and J. Richard Udry. "How much do mentally disabled adolescents know about sex and birth control." *Adolescent and Family Health* 3, no. 1 (2003): 28-38.



Case study of OPA Investigation – Ms K.

Ms K is a 19-year-old woman who has severe physical and intellectual disabilities that she acquired when she suffered meningitis as an infant. Ms K has very limited communication and comprehension and she requires full support with all aspects of daily life.

Ms K's parents said she was finding her periods very painful and she experienced heavy bleeding for all but several days per month. They stated it was difficult for them to manage her menstruation. After visits to the GP, a gynaecologist and surgeon, Ms K was listed for surgery at a public hospital.

Only VCAT has the legal authority to consent to a medical procedure that will result in infertility and where the patient cannot give informed consent to the procedure. The parents were assisted by the hospital to apply for VCAT's approval for the surgery. VCAT referred the matter to OPA to investigate and report on the need for a hysterectomy.

A variety of views as to Ms K's wellbeing were revealed. Independent assessments established that her periods were normal, and the medical need to perform the hysterectomy could not be established. Other less intrusive responses had not been trialled. VCAT did not consent to the hysterectomy. This was a complex matter that required careful enquiry to uncover the real situation for Ms K.

The case highlighted the difficulty for guardians, carers and medical practitioners in forming accurate understandings when the person with disability cannot clearly indicate whether they are experiencing pain or discomfort, and where that pain might be located. Ms K's experience was being voiced by her parents, but they had strong beliefs about the situation and it was inevitable that they were influenced by their carer role and distress at their daughter's condition. Cultural and religious beliefs also needed to be considered. In addition, there were issues associated with the use of interpreters and differing opinions as to who had actually proposed what.

Both parents had very serious health issues and their ability to continue caring was at question when they discussed their daughter's condition. It was clear that this had also influenced the medical practitioners' consideration of surgery. The practitioner confirmed that they would not consider performing the same procedure for a woman who did not have an intellectual disability.

OPA has continued to work with Ms K, her parents and their supports. Ms K's access to activities has been restored. Extra services have been applied for and referral to a female medical practitioner with a strong background in disability and gynaecology was accepted.

- 4.10. This case study highlights the continuing serious concern that medical practitioners continue to offer surgery that would violate their patient's human rights and which they would not contemplate in cases of a woman not having a disability. It illustrates how the personal inviolability of an individual with disability can be potentially violated when medical practitioners are asked by parents to provide a medical solution – hysterectomy – for what is essentially a social problem, a need for increased services



and supports. It also highlights that VCAT oversight provides effective safeguards, when this authority is sought.

- 4.11. Primary health care needs to better respond to the informational and related support needs of people with intellectual disabilities, and other cognitive disabilities. Current training and professional development is insufficient and needs to be significantly expanded. In Victoria, the Centre for Developmental Disability Health promotes better outcomes through educational, research and clinical activities.¹⁰ The extent and reach of this kind of professional development and clinical support needs to be more widely available in Victoria and across Australia.
- 4.12. Funded specialist disability information and referral services currently perform the important function of providing good and independent information about disability service systems and support. Importantly, they are able to provide this peer support and information to families and individuals when they first encounter the impact of disability, from outside a medical framework, and usually from a self-help and social inclusion perspective. Within present funding arrangements, state and territory governments have the responsibility for funding disability information, referral and self-help services of this type. Examples of small organisations receiving some limited state government funding in Victoria include Down Syndrome Victoria and the Cerebral Palsy Support Network.¹¹ Other elements of the service system also look to these services for information. It is vital that this kind of support continue to be available, and that funding is adequate and commensurate with demand.

RECOMMENDATIONS

3. That the primary health care professional bodies review the adequacy of the current guidance, training and specialist support available to practitioners, and that they ensure their members are fully equipped to recognise the presence of cognitive impairment, understand its implications for decision-making capacity, and provide professional services in conformance with contemporary legal and human-rights requirements.
4. That sexual health and family planning services target and give priority to providing effective counseling, education and related support to people with a cognitive impairment and their families.

¹⁰ Information available at <http://www.cddh.monash.org/>, accessed 14 January 2013.

¹¹ Information available at <http://www.downsyndromevictoria.org.au/> and <http://www.cpsn.info/>, accessed 16 January 2013



5. That state and territory governments provide targeted resources to funded sexual health and family planning services that they acquit for by demonstrating continuing additional services to people with a cognitive impairment.
6. That state and territory governments provide financial assistance to appropriate non-government organisations to produce community education materials, and best-practice policy frameworks, which promote a positive message of the sexuality of people with disabilities, within a human rights framework.
7. That all specialist disability services providing support to children and adults with decision-making support needs ensure they are supporting maximal opportunities for their clients to explore friendships, social relationships and their own sexual identity and attraction in the ways typical of their peers who do not have an identified disability.
8. That within the present funding arrangements, state and territory governments ensure through quality assurance, service monitoring and funding arrangements that funded specialist disability services are required to support maximal opportunities for their clients to explore friendships, social relationships and their own sexual identity and attraction in the ways typical of their peers who do not have an identified disability.
9. That within the present funding arrangements, state and territory governments ensure families and individuals have continuing access to good information about disability service systems and support, at the earliest possible stage after the impact of disability is first recognised, from adequately funded disability information, referral and self-help services.



5. Prevalence of sterilisation practices

- 5.1. In this section, OPA addresses the following term of reference: *(b) the prevalence of these sterilisation practices and how they are recorded across different state and territory jurisdictions.*
- 5.2. OPA has reviewed its involvement in sterilisation cases over the last five years. This data shows that on average there were seven applications per year during this recent five-year period.
- 5.3. This seems to represent a slight increase from earlier periods with OPA identifying 60 cases (five per year) for the twelve year period 1992 — 2004.¹²
- 5.4. The data for the period 2008 — 2012 is presented in the three tables below.

Tables: Sterilisation applications to VCAT, 2008 — 2012¹³

Year	Female	Male	total VCAT applications
2008	4	-	4
2009	8	2	10
2010	7	-	7
2011	7	-	7
2012	5	2	7

Year	VCAT consent given for procedure			VCAT consent refused		
	Female	Male	Total	female	male	total
2008	3	-	3	0	-	0
2009	4	1	5	1	0	1
2010	4	-	4	0	-	0
2011	3	-	3	2	-	2
2012	2	2	4	1	0	1

¹² Natalie Tomas, *The reproductive rights of women with disabilities* (2004)

¹³ The data presented is limited to those cases referred to OPA by VCAT.



Year	VCAT application Dismissed			VCAT application withdrawn		
	female	Male	Total	female	Male	total
2008	0	-	0	1	-	1
2009	1	1	2	2	0	2
2010	3	-	3	0	-	0
2011	1	-	1	1	-	1
2012	0	0	0	2	0	2

- 5.5. This data shows that VCAT provided consent in 40% of cases brought before it during this five-year period. OPA's review of these particular cases indicates that these applications are for 'special medical procedures' that would be termed 'therapeutic', using the terminology of the decision in *Marion's Case*.
- 5.6. For the other 60% of applications during this period, VCAT refused to provide consent in fewer cases than those dismissed or withdrawn. Our brief review of the cases suggests that applications were typically withdrawn when the OPA investigation showed that no need has been established, or that less restrictive alternatives had not yet been pursued. Applications were typically dismissed because the individual's incapacity to provide consent had not been demonstrated.
- 5.7. The data presented above only relates to applications received by VCAT, and referred to OPA. Sterilisation procedures may have occurred in Victoria without VCAT authorisation.
- 5.8. In the complex and under-resourced medical system, valid, reliable and consistent categorisation of procedures and persons are absent, compromising assessments of the number of procedures that are occurring without authorisation. Deriving an accurate picture of the number of procedures actually occurring requires further research and the development of appropriate measures.
- 5.9. This absence of good data should not delay action to remedy the current situation as the more important issues is the protection of the bodily integrity and human rights of girls and women with disability.

RECOMMENDATIONS

10. That relevant research-related bodies, such as the National Health and Medical Research Council, the Australasian Society for the Study of Intellectual Disability, and the Centre for Developmental Disability Health, explore how more research can be conducted on the sterilisation of people with disabilities and related topics.



6. Adequacy of current legal, regulatory and policy frameworks

6.1. In this section, OPA addresses the following term of reference:

(d) whether current legal, regulatory and policy frameworks provide adequate:

- (i) steps to determine the wishes of a person with a disability,*
- (ii) steps to determine an individual's capacity to provide free and informed consent,*
- (iii) steps to ensure independent representation in applications for sterilisation procedures where the subject of the application is deemed unable to provide free and informed consent, and*
- (iv) application of a 'best interest test' as it relates to sterilisation and reproductive rights.*

6.2. The Australian Guardianship and Administration Council (AGAC) has published a *Protocol for Special Medical Procedures (Sterilisation) 6 May 2009* which is observed in Victoria and elsewhere in Australia.

6.3. The Victorian Civil and Administrative Tribunal (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.

6.4. OPA strongly supports VCAT's authority that it already has in relation to adults with disability being extended to include 'special medical treatment decisions' concerning children, and has made this recommendation above (Recommendation 2).

6.5. This could be done by extending VCAT's jurisdiction in Part 4A of the *Guardianship and Administration Act* to include children.

6.6. This would give VCAT concurrent jurisdiction with the Family Court of Australia to hear sterilisation applications regarding minors.

6.7. This extension would be consistent with the approach already taken in other states where guardianship legislation empowers the tribunal/board to make some medical decisions (such as sterilisation) concerning children with disabilities.

a) The continuing occurrence of sterilisation must be addressed by:

- i. better availability of information and professional development;
- ii. more effective legal avenues for the protection of human rights;
- iii. the provision of sufficient supports, including advocacy and legal advocacy support.

6.8. Our detailed responses and recommendations in relation to these terms of reference follow.

(i) Steps to determine the wishes of a person with a disability

6.9. Families may be resistant to or inexperienced in giving effect to their child's wishes and emerging adulthood.

- a) Families can be unused to the idea of their dependent child developing into an independent adult or may find the emerging sexuality of their child confronting.



- b) Families will often make almost all day-to-day decisions for their child, especially if they have very high support needs.
 - i. Parents may have chosen what their child eats, wears and does every day of their child's life.
 - ii. The developing child may have very little experience of making decisions for themselves, even for decisions with very few potential adverse consequences.
 - iii. Schools, both mainstream and special, have not dealt adequately with the issue of their students with cognitive impairment emerging adulthood and sexuality.
 - c) Asking a child or young adult what their wishes are when they have very little or no experience of autonomous decision making, especially for a decision with major consequences, is problematic.
 - d) Doctors and other health professionals may be used to dealing with the parents as the representative of the child, and not be experienced in dealing directly with the child to ascertain her wishes.
 - e) Parents may be used to relying on the opinions of health professionals, especially doctors, for guidance on their child's development and life-course chances.
 - f) Health professionals may not have much direct experience or knowledge of the everyday lives of people with disability, and the support arrangements and opportunities that are available.
 - g) Doctors and paediatricians might not have the experience or had the professional development opportunities to have developed experience and expertise in ascertaining a persons wishes in a non-directive and supportive manner, and may not recognise all the ethical issues involved.
 - h) Ascertaining the wishes of a child or young adult with intellectual disability requires time, skills and carefully considered approaches that is part of the professional expertise of advocates, guardians and social workers who are experienced, knowledgeable, and supervised in this work.
 - i) In Victoria, OPA is available to provide relevant information and support through our community education activities, and with further resources our role and reach could be expanded.
- 6.10. Similar dynamics and issues to those noted above in relation to children also apply to the situation of many adults with a cognitive impairment who experience high levels of dependency upon their families and carers.

RECOMMENDATION

11. That the Australian Institute of Health and Welfare, in partnership with other bodies, develops more detailed guidelines for the reporting of sterilisation procedures, which reliably distinguish between therapeutic and non-therapeutic procedures, to ensure as much consistency as possible in measurement and data collection, both within and between jurisdictions.



(ii) steps to determine an individual's capacity to provide free and informed consent

6.11. Many children with intellectual disability are not being provided with the information and support they need to develop and exercise their capacity. This issue particularly affects girls and young women.

- a) Doctors and paediatricians might not have received the necessary training or professional development to determine an individual's capacity to provide free and informed consent.
- b) The determination of whether an individual has capacity is ultimately a legal question, and not a medical determination.
- c) For the reasons discussed above, doctors may not be used to dealing directly with their young patient herself, and may not fully respond to all of her information and other needs.
- d) Research has shown that even women with mild intellectual disability do not necessarily understand the connection between menstruation and fertility. This may be true even for women who have already had pregnancies.
- e) The presence of cognitive impairment does not automatically mean that an adult woman is incapable of making such decision herself.
- f) If a doctor believes that consent has been provided by an adult woman with cognitive impairment, then the woman's consent authorises the performance of the procedure and VCAT consent (in Victoria) is not required.
- g) Doctors may mistakenly assume that informed consent has been freely given by a young adult — whose disability they may overlook — when the patient is actually unaware of the consequences of the procedure, or is merely complying with their parent's views or wishes without considering her or his own interests.

(iii) steps to ensure independent representation in applications for sterilisation procedures where the subject of the application is deemed unable to provide free and informed consent

6.12. OPA has been involved in these issues and proceedings for more than twenty-five years and has developed considerable professional expertise in investigating circumstances where an application for tribunal consent to 'special procedures' affecting women and men with cognitive impairment. OPA also has some experience when an application affecting minors has been made to the Family Court.

- a) Girls and women with cognitive impairment are more reliant on their families, and partners, for support than the norm. Due to this dependence they are at greater risk of social isolation, inadequate or inappropriate support and domestic violence or neglect.
- b) Independent and competent representation for the person affected is of the utmost importance.



(iv) application of a ‘best interest test’ as it relates to sterilisation and reproductive rights

- 6.13. In Victoria, s. 38 of the *Guardianship and Administration Act 1986* provides the legislative guidance for determining the best interest of the person for whom an application has been made.

Guardianship and Administration Act 1986 (Vic)

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.

[See all relevant GAA provisions in Appendix One below]

- 6.14. These legislated provisions in effect supply a checklist for investigators to follow when determining if the person’s best interests are being met.
- 6.15. Menstruation can be extremely difficult and traumatic for a very few girls and women with disability and it is conceivable that in some cases there may be no less restrictive alternative to sterilisation; but this must be fully tested in away that gives adequate weight to all of her human rights.
- 6.16. In such cases, it must be absolutely certain through exhaustion of less restrictive alternative treatments and incontrovertible evidence that it really would promote and maintain her health and well-being. The precise nature of proposed procedure and its hazards and perceived benefits must also be critically examined to see if these benefits can actually be achieved, or are only presumed, and what the other consequences may entail.



- 6.17. It is also important that the courts retain oversight of this best interest test as the rights and interests of the girl or woman affected can sometimes be confounded with the interest of other parties, especially parents or carers. Those who are directly involved, or commenting upon it, may not have a sophisticated enough view of all the rights and interests that need to be considered, and which of those need to be determinative.
- 6.18. In most cases, an alternative approach other than sterilisation, will better protect her well-being and all of her reproductive and other rights.

RECOMMENDATION

12. That the Federal, State and Territory Governments ensure individuals with disabilities and their families have good access to independent advocacy, including legal advocacy, through a significant expansion in funding for this purpose. This advocacy support must focus on addressing the social and personal wellbeing of the person with disabilities.



7. Impacts of sterilisation of people with disabilities

- 7.1. In this section, OPA addresses the following term of reference: *(e) the impacts of sterilisation of people with disabilities.*
- 7.2. OPA notes the report produced in 2012 by Carolyn Frohmader and Christina Ryan for Women With Disabilities Australia, 'Moving forward and gaining ground: The sterilisation of women and girls with disabilities in Australia'.¹⁴
- 7.3. On page seven they quote what some women have said, including the following:
- i. I haven't had the chance to grieve the loss of a part of me that should have been mine to choose whether I keep it or not.
 - ii. I was sterilised at 17. Someone else made the decision for me. I didn't object because I had been led to believe that people with disabilities were worthless and that they were a burden on people and society. I felt that if I produced a child with a disability I would be producing a 'bad' person.
 - iii. I was sterilised at the age of 18 without my consent. I still feel devastated by what happened because I will never be able to have children.
- 7.4. Commonwealth, States and Territories must adequately protect the personal inviolability of people with disabilities through law and sanctions.

¹⁴ Paper written by Carolyn Frohmader, and adapted for presentation and delivered by Christina Ryan on behalf of Women With Disabilities Australia (WWDA) to the International Conference 'Challenges in the new millennium for women with disabilities', Madrid, 27th – 29th June 2012. Available from <http://www.wwda.org.au/sterilise2011.htm>, accessed 29 January 2013



8. Australia's compliance with international obligations

- 8.1. In this section, OPA addresses the following term of reference: *(f) Australia's compliance with its international obligations as they apply to sterilisation of people with disabilities*
- 8.2. Australia is not compliant with the United Nations Convention on the Rights of Persons with Disabilities, and potentially in breach of the following articles:
- Article 3 - General principles
 - Article 6 - Women with disabilities
 - Article 7 - Children with disabilities
 - Article 8 - Awareness-raising
 - Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment
 - Article 16 - Freedom from exploitation, violence and abuse
 - Article 17 - Protecting the integrity of the person
Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.
 - Article 23 - Respect for home and the family
1.(f) Persons with disabilities, including children, retain their fertility on an equal basis with others.
 - Article 25 - Health
 - Article 26 - Habilitation and rehabilitation
- 8.3. Non-consensual sterilisation also means that Australia is not compliant with Articles 7, 17 and 24 of the *International Covenant on Civil and Political Rights*.¹⁵
- 8.4. The sterilisation of a child that is not performed for an appropriate medical reason will also mean that Australia is in breach of Article 19 of the *Convention on the Rights of the Child*.¹⁶

¹⁵ 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

¹⁶ Ibid



9. Factors leading to sterilisation procedures being sought

9.1. In this section, OPA addresses the following term of reference:

(g) the factors that lead to sterilisation procedures being sought by others for people with disabilities, including:

(i) the availability and effectiveness of services and programs to support people with disabilities in managing their reproductive and sexual health needs, and whether there are measures in place to ensure that these are available on a non-discriminatory basis,

(ii) the availability and effectiveness of educational resources for medical practitioners, guardians, carers and people with a disability around the consequences of sterilisation, and

(iii) medical practitioners, guardians and carers' knowledge of and access to services and programs to support people with disabilities in managing their reproductive and sexual health needs.

9.2. As has been noted above in Section Four, there are historical, cultural and social tendencies that are harmful to people with disabilities, including eugenic thinking, which affect individuals, families and health provider's responses to the emergent and actual sexuality and adulthood of their child or client.

(i) the availability and effectiveness of services and programs to support people with disabilities in managing their reproductive and sexual health needs, and whether there are measures in place to ensure that these are available on a non-discriminatory basis.

9.3. There is inadequate provision of services and programs to support people with disabilities in managing their reproductive and sexual health needs.

9.4. People with intellectual disability need information to be presented simply in plain English and simple English, and for this to be repeated across a long time frame.

9.5. Accessible education and information on sexual and reproductive health needs to be provided to girls and women with disability as they develop into adulthood and beyond.

9.6. In Victoria, there has been a reduction in the availability of specialised counselling and information services for the reproductive health needs of women with a cognitive impairment. For example, OPA understands that the specialised support available from Family Planning Victoria has reduced over time.

9.7. The importance of specialised resources is of increasing importance given the policy shift to individualised service approaches for people with cognitive impairment which depends on comprehensive, accessible and responsive specialised and mainstream services.

9.8. Specialised services do have the potential advantage of building a body of expertise and knowledge in the diverse issues impacting upon their client group, but given the large level of unmet need in the community, not every girl or woman with a cognitive impairment will be receiving support from formal disability services.



- 9.9. The quality of support, and respect for the human rights of the people receiving services, is also under a lot of pressure from high demand and inadequate funding.
- 9.10. Girls, and many women with a cognitive impairment, need assistance to attend health services and medical appointments. When disability support workers, social workers, or other professionals are involved they will need to ensure that she is getting accessible information concerning their reproductive health. Passive support may not be sufficient. A proactive approach, involving prior discussion and prompting, will ensure that her lack of knowledge or unfamiliarity with all the issues involved does not prevent her from getting the health treatment or advice that she needs.
- 9.11. This last issue means that funding and support allocations must include in their design sufficient attention to the needs of girls and women with a cognitive impairment arising for maintaining their reproductive health.
- 9.12. In our modern Western culture, it is the norm that children are uncomfortable in discussing matters relating to their sexuality, such as contraception, with their doctor in the company of her parents. This raises issues for doctors when they are seeing a young patient with a cognitive impairment accompanied by her parents, whom then also represent her interests. It should be apparent to the doctors that this atypical situation might not be ideal for their patient, and that alternative advocacy support for the girl or young woman might offer her greater independence. This issue of the availability of independent advocacy should be identified by the doctor or health service, and potential avenues and options discussed with the parents.
- 9.13. The comments made above in relation to women also apply to boys and men.
- 9.14. OPA is aware of a case where a man with intellectual disability, fully able to provide informed consent to the performance of a vasectomy, was denied access to this surgery because of the presence of his disability, even though his disability did not raise capacity issues. This man was in a stable relationship and did not want to father any more children, like many other men without disability in similar circumstances. This case shows that the discrimination faced by people with disabilities has a variety of expressions.
- 9.15. Some men with intellectual disabilities who have histories of sexual offending, may be prescribed anti-libidinal medication (In Victoria subject to provisions in the Disability Act 2006 – conditions of a supervised treatment order). This treatment may have consequences for their fertility. Various protections apply, including the potential for advocacy from the Office of the Public Advocate. This must be the least restrictive available alternative.



(ii) the availability and effectiveness of educational resources for medical practitioners, guardians, carers and people with a disability around the consequences of sterilisation

- 9.16. Formally appointed guardians who have the support of a body such as the Office of the Public Advocate, and the benefits of its professional development, will have an excellent knowledge of the consequences of sterilisation, and will be fully informed of alternatives.
- 9.17. It cannot be expected that in the current situation where generic health services are dealing with complex situations and expectations that they will have a good awareness of specialised educational resources that might be of assistance to themselves or families.
- 9.18. Ethical practitioners will seek out the information they need but this might be difficult in time-pressured situations.
- 9.19. There needs to be increased training of medical practitioners in these ethical and legal issues as currently they may only have had a few hours of specific training in these issues over the period of their student training.
- 9.20. Parents will expect their doctors and other professionals, such as special education teachers, to be aware of all the legal and ethical issues involved but this trust may currently be unwarranted. The professionals may also be reluctant to challenge parent's views, believing that the parents have authority to make such decisions when these have been reserved for the courts.
- 9.21. Specials schools and mainstream schools may not provide adequate sex education and human relationships counselling on relationships and social and legal expectations of relationships to the pupils and their parents. Schools may be reluctant to broach these topics with defensive or disinterested parents.
- 9.22. These issues have been addressed in recommendations made above.

(iii) medical practitioners, guardians and carers' knowledge of and access to services and programs to support people with disabilities in managing their reproductive and sexual health needs

- 9.23. Formally appointed guardians who have the support of a body such as the Office of the Public Advocate, and the benefits of its professional development, have an excellent knowledge of the limited available services and programs.
- 9.24. It cannot be expected that in the current situation where services are fragmented and under resourced that families or treating medical practitioners will have a good awareness of services outside their immediate experience. These issues have been addressed in recommendations made above.
- 9.25. These issues have been addressed in recommendations made above.



10. Other related matters

- 10.1. In this section, OPA addresses the following term of reference: *(h) any other related matters*.
- 10.2. Sterilisation of women and girls with disability is an emblematic issue in that its occurrence signifies serious everyday discrimination and dignity issues affecting people with intellectual disability of all degrees of severity, which give rise to precarious lives. While fewer women and girls with intellectual disability may now be subjected to surgical sterilisation procedures the lack of positive attention to their information and other needs is having other highly detrimental results such as poverty, child protection involvements, and pregnancy terminations.
- 10.3. A comprehensive approach needs to be taken, which involves information and counselling, health services, and peer, advocacy and related support, to assist people with intellectual disability to better manage their sexual and reproductive health.
- 10.4. The view that sterilisation is not a legal problem, and should be dealt with privately by the person with a disability and their family and doctors, is factually incorrect. Australia's common law heritage, including the social protection doctrine of *parens patriae*, and its obligations under international law, require state action on this issue to protect vulnerable people with disabilities from harm, including harm that is superficially beneficent and well-intended.
- 10.5. In simple terms, the individual's bodily integrity must be protected by the state, including from the intentions of parent's or doctors who incorrectly think that they have authority in these matters.
- 10.6. We are very concerned that the incidence of violence against vulnerable people with disability appears to be on the rise. The coercive sterilisation of an individual with disabilities when this is not in their best interest is an assault and an act of violence. This issue must firstly be addressed through prevention, via a range of responses as has been discussed, and where that has failed through investigation and prosecution.
- 10.7. OPA supports the criminalisation of procuring or abetting the coercive sterilisation of people with disabilities, that lacks Australian judicial authority, regardless of where the procedure may occur.
- 10.8. The introduction of the National Disability Insurance scheme (NDIS) presents an opportunity to address some of the inadequacies of the service support system. The NDIS will have to address some of the shortcomings of present mainstream services, or there will be continuing neglect of some of the needs that lead to the continuing unlawful sterilisation of people with disabilities.
- 10.9. For example, the NDIS will need to ensure that appropriate support is available to people with disabilities to perform their parenting role, and from mainstream sexual health and pregnancy counselling services.



RECOMMENDATIONS

13. That government enacts legislation to make procuring or abetting the coercive sterilisation of people with disabilities without judicial authority a criminal offence, with serious penalties for conviction.
14. That the Australian Government ensures the design and operation of the National Disability Insurance Scheme (NDIS) accommodates the issues raised in this submission and its recommendations.



11. 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.

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