

# Appendix 1: FIGO Guidelines

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## **FEMALE CONTRACEPTIVE STERILIZATION**

### **Background**

1. Human rights include the right of individuals to control and decide on matters of their own sexuality and reproductive health, free from coercion, discrimination and violence. This includes the right to decide whether and when to have children, and the means to exercise this right.
2. Surgical sterilization is a widely used method of contraception. An ethical requirement is that performance be preceded by the patient's informed and freely given consent, obtained in compliance with the Guidelines Regarding Informed Consent (2007) and on Confidentiality (2005). Information for consent includes, for instance, that sterilization should be considered irreversible, that alternatives exist such as reversible forms of family planning, that life circumstances may change, causing a person later to regret consenting to sterilization, and that procedures have a very low but significant failure rate.
3. Methods of sterilization generally include tubal ligation or other methods of tubal occlusion. Hysterectomy is inappropriate solely for sterilization, because of disproportionate risks and costs.
4. Once an informed choice has been freely made, barriers to surgical sterilization should be minimised. In particular: a) sterilization should be made available to any person of adult age; b) no minimum or maximum number of children may be used as a criterion for access; c) a partner's consent must not be required, although patients should be encouraged to include their partners in counseling; d) physicians whose beliefs oppose participation in sterilization should comply with the Ethical Guidelines on Conscientious Objection (2005).
5. Evidence exists, including by governmental admission and apology, of a long history of forced and otherwise non-consensual sterilizations of women, including Roma women in Europe and women with disabilities. Reports have documented the coerced sterilization of women living with HIV/AIDS in Africa and Latin America. Fears remain that ethnic and racial minority, HIV-positive, low-income

and drug-using women, women with disabilities and other vulnerable women around the world, are still being sterilized without their own freely-given, adequately informed consent.

6. Medical practitioners must recognize that, under human rights provisions and their own professional codes of conduct, it is unethical and in violation of human rights for them to perform procedures for prevention of future pregnancy on women who have not freely requested such procedures, or who have not previously given their free and informed consent. This is so even if such procedures are recommended as being in the women's own health interests.
7. Only women themselves can give ethically valid consent to their own sterilization. Family members including husbands, parents, legal guardians, medical practitioners and, for instance, government or other public officers, cannot consent on any woman's or girl's behalf.
8. Women's consent to sterilization should not be made a condition of access to medical care, such as HIV/ AIDS treatment, natural or cesarean delivery, or abortion, or of any benefit such as medical insurance, social assistance, employment or release from an institution. In addition, consent to sterilization should not be requested when women may be vulnerable, such as when requesting termination of pregnancy, going into labor or in the aftermath of delivery.
9. Further, it is unethical for medical practitioners to perform sterilization procedures within a government program or strategy that does not include voluntary consent to sterilization.
10. Sterilization for prevention of future pregnancy cannot be ethically justified on grounds of medical emergency. Even if a future pregnancy may endanger a woman's life or health, she will not become pregnant immediately, and therefore must be given the time and support she needs to consider her choice. Her informed decision must be respected, even if it is considered liable to be harmful to her health.
11. As for all non-emergency medical procedures, women should be adequately informed of the risks and benefits of any proposed procedure and of its alternatives. It must be explained that sterilization must be considered a permanent, irreversible procedure that prevents future pregnancy, and that non-permanent alternative treatments exist. It must also be emphasized that sterilization does not provide protection from sexually transmitted infections. Women must be advised about and offered follow-up examinations and care after any procedure they accept.
12. All information must be provided in language, both spoken and written, that the women understand, and in an accessible format such as sign language, Braille and plain, non-technical language appropriate to the individual woman's needs. The physician performing sterilization has the responsibility of ensuring that the patient has been properly counseled regarding the risks and benefits of the procedure and its alternatives.

13. The U.N. Convention on the Rights of Persons with Disabilities includes recognition “that women and girls with disabilities are often at greater risk ... of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation”. Accordingly, Article 23(1) imposes the duty “to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:
  - a) The right of all persons with disabilities who are of marriageable age to marry and to found a family ... is recognized;
  - b) The rights...to decide freely and responsibly on the number and spacing of their children ...are recognized, and the means necessary to enable them to exercise these rights are provided;
  - c) Persons with disabilities, including children, retain their fertility on an equal basis with others”.

### **Recommendations**

1. No woman may be sterilized without her own, previously-given informed consent, with no coercion, pressure or undue inducement by healthcare providers or institutions.
2. Women considering sterilization must be given information of their options in the language in which they communicate and understand, through translation if necessary, in an accessible format and plain, non-technical language appropriate to the individual woman’s needs. Women should also be provided with information on non-permanent options for contraception. Misconceptions about prevention of sexually transmitted diseases (STDs) including HIV by sterilization need to be addressed with appropriate counseling about STDs.
3. Sterilization for prevention of future pregnancy is not an emergency procedure. It does not justify departure from the general principles of free and informed consent. Therefore, the needs of each woman must be accommodated, including being given the time and support she needs, while not under pressure, in pain, or dependent on medical care, to consider the explanation she has received of what permanent sterilization entails and to make her choice known.
4. Consent to sterilization must not be made a condition of receipt of any other medical care, such as HIV/AIDS treatment, assistance in natural or cesarean delivery, medical termination of pregnancy, or of any benefit such as employment, release from an institution, public or private medical insurance, or social assistance.
5. Forced sterilization constitutes an act of violence, whether committed by individual practitioners or under institutional or governmental policies. Healthcare providers have an ethical response in accordance with the guideline on Violence Against Women (2007).

6. It is ethically inappropriate for healthcare providers to initiate judicial proceedings for sterilization of their patients, or to be witnesses in such proceedings inconsistently with Article 23(1) of the Convention on the Rights of Persons with Disabilities.
  
7. At a public policy level, the medical profession has a duty to be a voice of reason and compassion, pointing out when legislative, regulatory or legal measures interfere with personal choice and appropriate medical care.

Goa, March 2011

# Appendix 2: Letter to the Australian Government from the United Nations Special Rapporteurs

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NATIONS UNIES  
HAUT COMMISSARIAT DES NATIONS UNIES  
AUX DROITS DE L'HOMME  
HUMAN RIGHTS

UNITED NATIONS  
OFFICE OF THE UNITED NATIONS  
HIGH COMMISSIONER FOR

PROCEDURES SPECIALES DU  
CONSEIL DES DROITS DE L'HOMME

SPECIAL PROCEDURES OF THE  
HUMAN RIGHTS COUNCIL

**Mandates of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and the Special Rapporteur on violence against women, its causes and consequences**

REFERENCE: AL Health (2002-7) G/SO 214 (89-15)  
AUS 2/2011

18 July 2011

Excellency,

We have the honour to address you in our capacities as Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and Special Rapporteur on violence against women, its causes and consequences pursuant to General Assembly resolution 60/251 and to Human Rights Council resolutions 15/22 and 16/7.

In this connection, we would like to bring to the attention of your Excellency's Government information we have received concerning **the alleged ongoing practice of non-therapeutic, forced sterilization of girls and women with disabilities in Australia.**

According to the information received:

It is alleged that non-therapeutic, forced sterilization is performed on young girls and women with disabilities for various purposes, including pregnancy prevention, population control, menstrual management and personal care. Reportedly, non-therapeutic sterilization is sterilization for a purpose other than to treat some malfunction or disease, and it refers to procedures carried out in circumstances that do not involve a serious threat to the health or life of the individuals. Forced sterilization refers to sterilization that has occurred in the absence of the individual's consent.

It is also alleged that cases of non-therapeutic, forced sterilization of girls have occurred in greater numbers than those formally authorized by courts and tribunals. It is further alleged that the existing State and Territory legislation and federal court mechanisms have not adequately addressed non-therapeutic, forced sterilizations of young girls with disabilities, in particular with regard to preventing such children from being taken out of Australia for sterilization procedures elsewhere.

While we do not wish to prejudge the accuracy of these allegations, we would appreciate information from your Government on the steps taken by the competent authorities with a view to ensuring

the right to the highest attainable standard of health of girls and women with disabilities. This right is enshrined, inter alia, in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ratified on 10 December 1975), which provides for the right of everyone to the enjoyment of the highest attainable standard of mental and physical health. This includes an obligation on the part of all States parties to ensure that health facilities, goods and services are accessible to everyone, especially the most vulnerable or marginalized sections of the population, without discrimination. In that connection, General Comment No. 14 of the Committee on Economic, Social and Cultural Rights elucidates that the right to health contains both freedoms and entitlements and holds that “the freedoms include the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation” (para. 8). I would also like to refer your Excellency’s Government to General Comment No. 5 of the Committee, which holds that “Women with disabilities also have the right to protection and support in relation to motherhood and pregnancy... Both the sterilization of, and the performance of an abortion on, a woman with disabilities without her prior informed consent are serious violations of article 10 (2) [of the International Covenant on Economic, Social and Cultural Rights]” (para.30).

We would like to draw the attention of your Excellency’s Government to Article 17 of the Convention on the Rights of Persons with Disabilities (ratified on 17 July 2008), which states: “Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others”. We would also like to refer your Excellency’s Government to Article 23 of the Convention, which holds that “States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that: (...) The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized.”

Furthermore, we would like to draw the attention of your Excellency’s Government to Article 24 of the Convention on the Rights of the Child (ratified on 17 Dec 1990), which holds that “States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health”. I would also like to refer your Excellency’s Government to General Comment No.9 of the Committee of the Rights of the Child which states: “The Committee is deeply concerned about the prevailing practice of forced sterilisation of children with disabilities, particularly girls with disabilities. This practice, which still exists, seriously violates the right of the child to her or his physical integrity and results in adverse life-long physical and mental health effects. Therefore, the Committee urges States parties to prohibit by law the forced sterilisation of children on grounds of disability.”

We would also like to refer your Excellency’s Government to General Recommendation No. 18 of the Committee on the Elimination of Discrimination against Women, which recommends that “States parties [to the Convention in the Elimination of all Forms of Discrimination against Women (ratified on 28 July 1983)] provide information on disabled women in their periodic reports, and on measures taken to deal with their particular situation, including special measures to ensure that they have equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life”. In that context, I would like to note paragraph 43 of the Concluding observations of the Committee on the Elimination of Discriminations against Women (CEDAW/C/AUL/CO/7, 30.07.2010) which recommended that Australia “enact national legislation prohibiting, except where there is a serious threat to life or health, the use of sterilization of girls, regardless of whether they have a disability, and of adult women with disabilities in the absence of their fully informed and free consent”.

Finally, we deem it appropriate to make reference to Commission on Human Rights Resolution 2005/41 on the Elimination on Violence against women, which provides that women should be empowered to protect themselves against violence and, in this regard, stresses that women have the right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence. In this context, we would also like to draw your attention to the Platform for Action of the Beijing World Conference on Women and the Programme of Action of the Cairo International Conference on Population and Development, which reaffirm the basic right

of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so.

We urge your Excellency's Government to take all necessary measures to ensure the protection and full enjoyment of the right to the highest attainable standard of health for girls and women with disabilities in accordance with international standards.

It is our responsibility under the mandate provided by the Human Rights Council to seek to clarify all cases brought to my attention regarding the right to health. Since we are expected to report on these cases to the Council, we would be grateful for your cooperation in addressing the following matters:

1. Are the facts alleged in the above summary of the case accurate?
2. Please provide details of any actions to prevent further non-therapeutic, forced sterilization of girls and women with disabilities?
3. Please provide details of any actions to sanction medical staff carrying out illegal non-therapeutic, forced sterilizations of girls and women with disabilities. Please provide details, and where available the results, of any investigation and judicial or other inquiries carried out in relation to such cases. If no inquiries have been made, or if they have been inconclusive, please explain why.
4. Please provide details of any actions to ensure that reparation, including compensation and rehabilitation, is provided to those girls and women with disabilities who may have been forcibly sterilized?
5. Please provide details of any actions to ensure that informed consent requirements are adequately implemented for all medical interventions with regard to children and persons with disabilities?
6. What measures are being taken to ensure the enjoyment of the right to health of girls and women with disabilities?

We undertake to ensure that your Excellency's Government's response to each of these questions is accurately reflected in the reports that will be submitted to the Human Rights Council for its consideration.

Please accept, Excellency, the assurances of our highest consideration.

Anand Grover  
Special Rapporteur on the right of everyone to the enjoyment of the  
highest attainable standard of physical and mental health

Rashida Manjoo  
Special Rapporteur on violence against women, its causes and consequences

# Appendix 3: Responses from the Australian Government to the United Nations Special Rapporteurs

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Note Number: 108/2011

The Australian Permanent Mission to the United Nations in Geneva presents its compliments to the Office of the High Commissioner for Human Rights, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and the Special Rapporteur on violence against women, its causes and consequences.

The Australian Government has the honour to refer to the Special Rapporteurs' letter of 18 July 2011 requesting the Australian Government's observations on the alleged practice of non-therapeutic, forced sterilisation of girls and women with disabilities in Australia.

The Australian Government is currently considering the information and questions contained in the letter. The Government is consulting with relevant stakeholders, including state and territory governments, and will provide a full response by 17 October 2011.

The Australian Permanent Mission to the United Nations avails itself of this opportunity to renew to the Office of the High Commissioner for Human Rights and the Special Rapporteurs the assurances of its highest consideration.



Geneva  
12 August 2011







Note Number: 127/2011

The Australian Permanent Mission to the United Nations in Geneva presents its compliments to the Office of the High Commissioner for Human Rights, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and the Special Rapporteur on violence against women, its causes and consequences.

The Australian Government has the honour to refer to the Special Rapporteurs' letter of 18 July 2011 requesting the Government's response regarding the alleged practice of non-therapeutic, forced sterilisation of girls and women with disabilities in Australia.

The Australian Government has the further honour to refer to its correspondence of 12 August 2011, in which the Special Rapporteurs were informed that a response would be provided by the Australian Government by 17 October 2011.

The Australian Government is currently considering the information and questions contained in the letter of 18 July 2011. The Commonwealth Attorney-General's Department is in the process of compiling a detailed Australian Government response to this request for information.

The Australian Government regrets that in order to ensure the Australian Government's response to this request is as comprehensive as possible, further consultation with the State and Territory governments is required, and consequently it is unlikely that this consultation will be completed before the earlier indicated date for submission of 17 October 2011.

The Australian Government is committed to upholding its international obligations and would prefer to take more time to ensure an accurate and fully considered response can be prepared on this important topic.

The Australian Government regrets this delay in response and will submit its final response to the Special Rapporteurs by 16 December 2011.

The Australian Permanent Mission to the United Nations avails itself of this opportunity to renew to the Office of the High Commissioner for Human Rights and the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and the Special Rapporteur on violence against women, its causes and consequences.



**OHCHR REGISTRY**

5 OCT. 2011

Recipients : ... *S.P.O.* ...  
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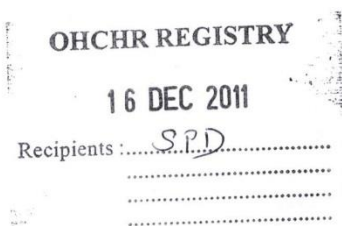
Note number: 185/2011

The Australian Permanent Mission to the United Nations in Geneva presents its compliments to the Office of the High Commissioner for Human Rights, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and the Special Rapporteur on violence against women, its causes and consequences.

The Australian Government has the honour to refer to the Special Rapporteurs' letter of 18 July 2011 requesting the Government's response regarding the alleged practice of non-therapeutic, forced sterilisation of girls and women with disabilities in Australia.

The Australian Government has the further honour to enclose, for the Special Rapporteurs' consideration, its response to the issues raised in that letter.

The Australian Permanent Mission to the United Nations avails itself of this opportunity to renew to the Office of the High Commissioner for Human Rights and the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and the Special Rapporteur on violence against women, its causes and consequences.



## **United Nations Office of the High Commissioner for Human Rights**

### **Special Rapporteurs' request for information -**

#### **Allegations of non-therapeutic forced sterilisation of girls and women with disabilities in Australia**

Australia is party to the Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), and the Convention on the Rights of the Child (CRC).

The Australian Government welcomes the Special Rapporteurs' interest in Australian law and practice concerning sterilisation.

Australia has recently submitted its initial report under the CRPD and, as that report notes, persons with disabilities are highly valued members of Australian communities and workplaces and make a positive contribution to Australian society. Moreover, the Australian Government is committed to improving and enriching the lives of all women to enable them to participate equally in all aspects of Australian life.

The Australian Government notes that the issue of Australian practices in relation to sterilisation of people with disabilities was raised in the course of Australia's recent Human Rights Universal Periodic Review (UPR).<sup>1</sup> In response to concerns expressed internationally and domestically, the then Commonwealth Attorney-General undertook to initiate further discussions with State and Territory counterparts on this issue. This consultation is ongoing at this time.

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<sup>1</sup> The Text of UPR recommendation P- 86.39 is available online at: [http://www.upr-info.org/IMG/pdf/recommendations\\_to\\_australia\\_2011.pdf](http://www.upr-info.org/IMG/pdf/recommendations_to_australia_2011.pdf)

## **1. Are the facts alleged in the summary of the case accurate?**

The Australian Government is committed to respecting the human rights of all persons with disabilities, including their right to personal integrity and reproductive rights. Sterilisation is a serious and irreversible procedure. Many people choose sterilisation as a method for controlling their fertility, but sterilisation can have significant physical and psychological consequences for those who undergo it. Sterilisations should never be carried out in the absence of a person's free and informed consent where that person is capable of making the decision, including where a person requires support to make that decision.

The Government takes its international human rights obligations seriously and has noted the concerns raised domestically and internationally regarding Australia's approach to sterilisation of children and adults with disabilities. The former Attorney-General has asked the Attorney-General's Department to consider options for reform in this area and has undertaken to raise this issue with State and Territory counterparts. This work will form part of the Government's National Human Rights Action Plan, the draft of which was launched to coincide with International Human Rights Day, 10 December 2011.

Under current laws, for children and adults who have an impaired capacity to consent and are unable to make an independent decision about whether to undergo a sterilisation procedure, Australian laws provide for authorisation by a court or guardianship tribunal. These laws are designed to protect the rights of those involved and to ensure procedures are authorised only where they are in the person's best interests.

Detail of the different laws governing sterilisation in Australia is set out below, however, broadly, in all Australian jurisdictions the authorisation of a court or tribunal is required in cases where a sterilisation procedure is not considered to be clearly therapeutic (the requirements vary between jurisdictions but would include, for example, surgery to remove a cancer). This is a greater protection than is applied for most other medical treatments, recognising the serious nature of sterilisation procedures and the possible challenges for carers to objectively determine what is in the person's best interests.

Courts and tribunals hear a range of evidence; often including the views of the person concerned, medical evidence and evidence from carers. In many cases, an independent advocate is appointed to represent the person's interests to the court or tribunal. Appointment of an independent advocate is usually a matter for the Court or Tribunal to decide. Sterilisations are authorised only where they are the last resort, as less invasive options have failed or are inappropriate, and where they are in the person's best interests.

A review conducted at the behest of the Standing Committee of Attorney General's (SCAG), the national ministerial council made up of the Australian Attorney-General and the State and Territory Attorneys-General, indicated in 2006 that sterilisations of children with an intellectual disability had declined significantly since Australia's 1997 country report to the Committee on the Elimination of All Forms of Discrimination Against Women. Evidence also indicated that alternatives to surgical procedures to manage the menstruation and contraceptive needs of girls and women with disabilities are increasingly available and seem to be successful in the most part.

The Australian Government recognises that the issues faced by children and women with disabilities and their parents and carers in these situations are sensitive, and that members of the community have strong concerns about children and women with disabilities being subjected to medical procedures which result in sterilisation.

The Australian Government would be very concerned if concrete evidence were made available that demonstrated that current mechanisms were not adequately protecting girls and women with disabilities, or that cases of sterilisation that are unlawful without court or tribunal authorisation had occurred in greater numbers than those formally authorised. The Australian Government would also be concerned if children with disabilities were being taken out of Australia for sterilisation procedures elsewhere that would be unlawful without court or tribunal authorisation in Australia. However the Australian Government is unaware of any such evidence at this time.

## **2. Please provide details of any actions to prevent further non-therapeutic, forced sterilisation of girls and women with disabilities.**

The Australian Government recognises the right of persons with disabilities to retain their fertility on an equal basis with others. Given its serious consequences sterilisation (of a child or of an adult with a disability who is unable to give consent), that is not performed to cure a disease or correct some malfunction, may only be authorised by a court or tribunal as a measure of last resort. In many cases, an independent advocate is appointed to represent the person's interests to the court or tribunal.

### ***A National Approach?***

Australia is a federation with nine separate jurisdictions, the Commonwealth or federal jurisdiction and eight State and Territory jurisdictions. The 2006 SCAG review considered model legislation on a nationally consistent approach, which would have applied to the authorisation procedures required for the lawful sterilisation of minors across all the jurisdictions.

After deliberation and the review of findings presented by a working group, it was decided that there would be limited benefit in developing such model legislation at that point in time. SCAG agreed instead to review State and Territory arrangements to ensure that all tribunals, or bodies with the power to make orders concerning the sterilisation of minors with an intellectual disability, are required to be satisfied before such an order is made that all less invasive alternatives to sterilisation are inappropriate or have been tried and found to be unsuccessful.

Subsequently, across the jurisdictions the legal framework currently applied to prevent unnecessary sterilisation of children and of women who are unable to independently consent differs. In 2011 the then Commonwealth Attorney-General undertook to initiate further discussions with State and Territory counterparts on this issue. These discussions are ongoing at this time and may influence future change to the Federal, State and Territory legal frameworks. In the interim, the following information outlines the current requirements in each jurisdiction.

### ***Commonwealth Jurisdiction***

At the federal level, the Family Court of Australia (Family Court) has jurisdiction under the *Family Law Act 1975* to make orders relating to the welfare of children, such as to authorise special medical procedures for children, including sterilisation that is not to treat a disease or correct some malfunction. The Family Court has a general welfare jurisdiction that enables the court to give consent to special medical procedures in place of the parents where the consent required is outside the bounds of parental authority. When considering a request the court must regard the child's best interests as the paramount consideration in these decisions. The following information outlines the approach taken by the courts in such cases.

Parent or guardian consent to sterilisation will be sufficient only where sterilisation is a by-product of surgery appropriately carried out to treat a malfunction or disease. In addition, a medical practitioner can lawfully carry out a sterilisation procedure in emergency situations, that is, where the procedure is necessary to save a person's life or to prevent serious damage to that person's health.

Where a child cannot consent due to a lack of maturity or a disability, court or tribunal approval is required for serious medical procedures including sterilisation. The Family Court is empowered to make such decisions, and in doing so is required to treat the best interests of the child as the paramount consideration

### **Marion's Case**

The High Court of Australia (HCA) established the framework for authorisation of sterilisation of children in Australia in *Secretary, Department of Health and Community Services v JWB and SMB (Marion's Case)* (1992),<sup>2</sup> on appeal from the Family Court. This appeal considered the processes required to authorise procedures that would render a 14 year old girl with intellectual disabilities infertile but prevent menstruation, pregnancy and hormonal fluxes and consequently reduce psychological and behavioural problems.

A majority judgement held that children who have a sufficient understanding and intelligence to enable them to understand fully what is proposed are capable of giving (or withholding) informed consent. The majority also held that where a child is insufficiently mature to give consent on his or her own behalf then, as a general rule, his or her parents or guardian have lawful authority to consent to medical treatment of the child, provided that the treatment is in the child's best interests.

The HCA acknowledged the uncertainty in the term 'therapeutic', but defined it to mean sterilisation that is 'a by-product of surgery appropriately carried out to treat some malfunction or disease.' The majority found that the parental power to consent to a sterilisation procedure is limited to circumstances in which sterilisation is therapeutic in this sense, because sterilisation 'requires invasive, irreversible and major surgery.'

Accordingly, only a court or tribunal, that has a relevant welfare jurisdiction, has the power to authorise sterilisation procedures that are not carried out as a by-product of surgery appropriately carried out to treat some malfunction or disease. The majority went on to provide guidance on the issues a court should consider when asked to give authorisation for such sterilisation and held that the court must decide 'whether, in the circumstances of the case, [authorisation of sterilisation] is in the best interests of the child' (the 'best interests test'). The HCA noted that within that context, sterilisation can only be authorised where other procedures or treatments are or have proved to be inadequate, have failed, or will not 'alleviate the situation so that the child can lead a life in keeping with his or her needs and capacities.'

Thus, a best interest test is applied by the Family Court throughout Australia when determining whether to authorise the sterilisation of a minor (*Marion's Case*). The *Family Law Rules 2004* set out evidence that must be considered in applying the best interests test. Additional details on these Rules are provided below. In addition, Family Court may appoint an independent children's lawyer to represent the child's best interests.

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<sup>2</sup> 175 CLR 218

## **Angela's Case**

An recent example of the application of the *Family Law Rules* and the test in *Marion's Case* can be found in *Re Angela (Special Medical Procedure)*, where the Family court authorised the performance of a hysterectomy on an eleven year old girl with a decision making disability.<sup>3</sup> Angela suffered from heavy menstrual bleeding and was anaemic. She also had epileptic seizures around the time of menstruation and menstruation brought pain, fatigue and hygiene discomfort. The judge found that Angela would 'never be in a position to make a decision about her own welfare'. Overall the judge was satisfied in this case that sterilisation was a last resort treatment that would contribute to an improvement in Angela's quality of life. The Family Court decided not to appoint an independent children's lawyer in this case.

## **Medicare Benefits**

In addition to the legal framework set up at the Commonwealth level to assess applications for sterilisation, there are additional protections provided through the regulations of the Medicare Benefits Schedule (MBS).

Through the MBS, the Australian Government facilitates universal access to allied health, general practice and specialist medical services by subsidising fee-for-service care. No Medicare benefits are payable for services which are provided in contravention of Commonwealth or State and Territory laws.

Medicare benefits are only payable for sterilisation procedures that are clinically relevant professional services as defined in Section 3(1) of the *Health Insurance Act 1973*. Section 3(1) states that a clinically relevant service must be provided by a medical practitioner in accordance with accepted medical practice.

The MBS does not provide any specific information on the sterilisation of the girls or women with disabilities, however, the following information is provided in relation to the sterilisation of minors:

- It is unlawful throughout Australia to conduct a sterilisation procedure on a minor which is not a by-product of surgery appropriately carried out to treat malfunction or disease (e.g. malignancies of the reproductive tract) unless legal authorisation has been obtained.
- Practitioners are liable to be subject to criminal and civil action if such a sterilisation procedure is performed on a minor (a person under 18 years of age) which is not authorised by the Family Court or another court or tribunal with jurisdiction to give such authorisation.

## ***State and Territory Jurisdictions***

In addition, the various Australian States and Territories have developed their own procedures for authorising the sterilisation of children and adults who do not have the capacity to consent on their own behalf. All States and Territories have their own procedures for adults, however New South Wales, Queensland, South Australia and Tasmania also have provisions for children. These procedures operate concurrently to the Family Court procedure for authorising sterilisations in the best interests of the child. The following information outlines the current legal requirements in various jurisdictions:

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<sup>3</sup> [2010] FamCA 98

## **New South Wales**

In NSW, two different legal regimes are in place to govern the sterilisation of children and adults. For children aged under 16, the provisions contained within section 175 of the *Children and Young Persons (Care and Protection) Act 1998* (NSW) apply. For people aged 16 and over who are incapable of giving consent to medical treatment, the regime under the *Guardianship Act 1987* (NSW) applies.

Under section 175(1) of the *Care and Protection Act 1998*, it is an offence to carry out special medical treatment on a child that is not in accordance with the provisions of this section. Special medical treatment includes non-therapeutic sterilisation, that is, medical treatment that is intended, or is reasonably likely to render a person permanently infertile. Section 175(2) of this Act provides that non-therapeutic sterilisation may only be performed in an emergency to save the child's life or prevent serious damage to health, or with the approval of the Guardianship Tribunal which must apply similar criteria when determining whether to give consent.

A person under 16 is entitled to be legally represented in proceedings before the Guardianship Tribunal. This representation is available free of charge through Legal Aid, with no means or merit tests applied.

Under the provisions of the *Guardianship Act 1987*, only the Guardianship Tribunal can consent to 'special treatment' of a person aged over 16 who is incapable of giving consent. Special treatment is defined to include 'any treatment that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out.'

Two exceptions apply under the provisions this Act:

- (a) The guardian of a patient may also consent to the carrying out of continuing or further special treatment if the Tribunal has previously given consent to the carrying out of the treatment and has authorised the guardian to give consent to the continuation of that treatment or to further treatment of a similar nature.
- (b) If the medical practitioner carrying out or supervising the treatment considers the treatment is necessary, as a matter of urgency to save the patient's life or to prevent serious damage to the patient's health.

The *Guardianship Act 1987* requires that the Tribunal must not consent to the carrying out of the treatment unless it is satisfied that it is the most appropriate form of treatment for promoting and maintaining the patient's health and well-being. Further, the Tribunal must not give consent to special treatment unless it is satisfied that the treatment is necessary to save the patient's life or to prevent serious damage to the patient's health.

The combined effect of the *Children and Young Persons (Care and Protection) Act 1998* and the *Guardianship Act 1987* is that no person under 16, regardless of competence, nor persons over 16 who are incapable of giving consent, can consent to a non-therapeutic sterilisation. Under this legal framework, it is beyond the scope of parents' or guardians' powers to consent on behalf of a child. Significant penalties of imprisonment for up to 7 years apply to persons who carry out unauthorised sterilisations under both Acts.

Decisions of the Tribunal about sterilisation or termination can be appealed to the Supreme Court of NSW which has the power to review such decisions and to set them aside or to make orders in substitution if it thinks fit.



## **Victoria**

Victorian legislation provides that involuntary treatments such as sterilisations and abortions can only be carried out by order of the Victorian Civil and Administrative Tribunal (VCAT).

Under the Victorian *Guardianship and Administration Act 1986* a 'special procedure' is defined to include: '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'; 'termination of pregnancy'; and 'any removal of tissue for the purposes of transplantation to another person'.

The *Guardianship and Administration Act 1986* sets out the manner in which the VCAT may consent to the performance of a 'special procedure' where the person in question is unable to give consent and the procedure would be in the patient's best interests. This Act only applies to a person who is aged 18 years of over.

The Victorian Office of the Public Advocate (OPA) must be given notice of any application and is entitled to participate in the case. The OPA's role in these applications is to assist VCAT to make a decision that is in a person's best interests by gathering information about the person's disability and their ability to make decisions about the proposed special procedure. The OPA is also occasionally involved as an amicus curiae, and sometimes even as a party, in Family Court cases where medical treatment decisions concerning children are being considered.

A decision of the Tribunal is reviewable by the superior courts. The *Guardianship and Administration Act 1986* provides quite severe penalties for any medical practitioner who carries out a special procedure without having obtained the proper consent.

While the *Guardianship and Administration Act 1986* is currently being reviewed by the Victorian Law Reform Commission, there is no indication at present that the Commission will make any recommendations to reform the provisions relating to obtaining consent for forced sterilisations and abortion.<sup>4</sup>

## **Queensland**

In Queensland where a health service or treatment is provided without a person's consent, the provider of the service may be liable to a criminal or civil prosecution. Where an adult has impaired capacity, a comprehensive substitute decision-making regime is established to provide the consent. For special health matters, such as a termination of pregnancy, sterilisation, removal of tissue while the adult is still alive, and participation in special medical research or experimental health care, only a Tribunal may provide consent for such a health matter and only in specified circumstances. These circumstances ensure that the adult's rights and interests are protected.

Queensland, like NSW, has an independent expert tribunal and separate legal representation of the child is provided by legal aid at no cost to the child. In Queensland, the Tribunal may consent to sterilisation of a child where:

- it is medically necessary;
- the child is likely to be sexually active and there is no reasonable method of contraception;

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<sup>4</sup> More information on the Victorian Law Reform Commission review of Guardianship is available online at: <http://www.lawreform.vic.gov.au/wps/wcm/connect/justlib/Law+Reform/Home/Current+Projects/Guardianship>

- the female child has menstruation problems and sterilisation is the only practicable way of overcoming the problems.

Further, the sterilisation cannot be reasonably postponed and must otherwise be in the child's best interests.

The Queensland medico-legal fraternity is well aware of the precedent set in *Marion's Case*. The requirement for permanent surgical sterilisation to deal with issues of fertility and menstrual problems in women with disabilities has been virtually eliminated by the availability of long acting, reversible implants referred to in the Royal Australian and New Zealand College of Obstetrics and Gynaecology (RANZCOG) Guidelines, see page 20.

### **Western Australia**

In Western Australia, there is no specific legislation concerning the sterilisation of children.

At common law, a child is capable of giving informed consent to medical treatment, including therapeutic and non-therapeutic sterilisation, when he or she is sufficiently mature and intelligent to understand fully the implications of the treatment proposed. Where a particular child, whether because of intellectual disability, or simply youth or immaturity, is incapable of giving a valid consent, then his or her parents (or other guardians) are authorised to consent to medical treatment, including therapeutic sterilisation. However, court authorisation is necessary for non-therapeutic sterilisation (*Marion's Case*). The criterion to be applied by a court with the necessary jurisdiction, is whether carrying out the procedure is in the best interests of the child.

The Western Australian *Guardianship and Administration Act 1990* requires that the consent of the State Administrative Tribunal is obtained for an adult with a decision-making disability who lacks capacity to give or refuse consent to sterilisation. A person has a right of appeal to the Supreme Court or Court of Appeal, and sterilisation is not able to proceed until all rights have been exhausted. Following the conclusion of any appeals, the treating doctor must have written consent from both the State Administrative Tribunal and the guardian.

In Western Australia, a therapeutic sterilisation (in very general terms) is a sterilisation which is the incidental result of surgery or treatment appropriately carried out to cure a disease or treat an injury whereas non-therapeutic sterilisation involves surgery or treatment carried out for the purpose of rendering the person infertile.

In relation to adults, the *Guardianship and Administration Act 1990* places limitations on the sterilisation of persons who are under guardianship and lack the capacity to consent to treatment. Under the *Guardianship and Administration Act 1990*, a person is prohibited from carrying out or taking part in any procedure for the sterilisation of a represented person, unless both the guardian and the State Administrative Tribunal have provided written consent to the sterilisation and all rights of appeal have lapsed or have been exhausted. The Tribunal may only consent to the sterilisation of a represented person if it is satisfied that it is in the best interests of that person. In addition to the guardianship provisions, the *Guardianship and Administration Act 1990* also provides that a person responsible (i.e. partner, closest adult relative or friend, or unpaid primary care provider) for a patient who is unable to make reasonable judgments in respect of any treatment proposed, cannot consent to the sterilisation of the patient.

A civil action in trespass and a criminal prosecution for assault may be brought against a health professional if medical treatment is given without consent. However, section 259 of the Western Australian *Criminal Code Act 1913* removes criminal responsibility for the administration in good

faith of medical treatment for a person's benefit if the treatment is reasonable, having regard to the person's state at the time and to all the circumstances of the case.

King Edward Memorial Hospital (KEMH) is Western Australia's public tertiary maternity, neonatal and gynaecological hospital. KEMH medical staff follow RANZCOG guidelines and refer cases where appropriate to the State Guardianship Board via the hospital's social work department. These generally include those patients requiring therapeutic sterilisation such as hysterectomy for menorrhagia

The Western Australian Health Hospital Morbidity Data System does not record any cases that are coded as non-therapeutic sterilisation in combination with a disability code. This includes both private and public hospital data.

### **South Australia**

The South Australian *Guardianship and Administration Act 1993* has provision to approve sterilisations where by reason of their mental incapacity (defined as: inability to look after his or her own health, safety or welfare...as a result of damage to, or any illness, disorder, imperfect or delayed development, impairment or deterioration of the brain or mind, or any physical illness or condition that renders the person unable to communicate his or her intentions or wishes) the person is deemed to be unable to make the decision for themselves.

Section 5 of the *Guardianship and Administration Act 1993* allows certain relatives to provide consent for medical or dental treatment, unless the treatment is defined as a 'prescribed treatment,' which is treatment that must not be carried out without the written consent of the South Australian Guardianship Board.

Under the *Guardianship and Administration Act 1993* 'prescribed treatment' includes medical treatments such as sterilisation and termination of pregnancy. In order for the South Australian Guardianship Board to approve 'prescribed treatment' it must satisfy the criteria in section 61.

The criteria include non-therapeutic treatment such as:

- No method of contraception that could ... reasonably be expected to be successfully applied; (Section 61(2)).
- Cessation of her menstrual cycle would be in her best interests (Section 61(2)).

### **Tasmania**

The *Guardianship and Administration Act 1995* provides a comprehensive and flexible statutory scheme for the authorisation and approval of medical and dental treatment for persons with a disability who are incapable of giving or refusing consent to treatment. The *Guardianship and Administration Act 1995* gives authority for the 'person responsible', who may be a spouse, carer or close friend of the person unable to give consent, to provide a substitute consent. However, the Guardianship and Administration Board (the Board) must consent to some types of very serious treatments, such as sterilisation.

The *Guardianship and Administration Act 1995* defines sterilisation as 'any treatment that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out' and makes it a special treatment under section 3. The Board's jurisdiction to deal with applications to consent to special treatment is provided by sections 44, 45 and 46 of the

*Guardianship and Administration Act 1995*. The Board's jurisdiction usually extends only to adults with disability, however in the area of sterilisation, the Board is the only body who may consent to this treatment for any person with a disability, including minors.

In giving consent, the Board must observe the principles set out in Section 6 of the *Guardianship and Administration Act 1995* which states:

'...a function or power conferred, or duty imposed, by this Act is to be performed so that -

- (c) the means which is the least restrictive of a person's freedom of decision and action as is possible in the circumstances is adopted; and
- (d) the best interests of a person with a disability or in respect of whom an application is made under this Act are promoted; and
- (e) the wishes of a person with a disability or in respect of whom an application is made under this Act are, if possible, carried into effect.

Section 45 of the *Guardianship and Administration Act 1995* sets out the following conditions upon which the Board may grant consent:

1. On hearing an application for its consent to the carrying out of medical or dental treatment the Board may consent to the carrying out of the medical or dental treatment if it is satisfied that-
  - (a) the medical or dental treatment is otherwise lawful; and
  - (b) that person is incapable of giving consent; and
  - (c) the medical or dental treatment would be in the best interests of that person.
2. For the purposes of determining whether any medical or dental treatment would be in the best interests of a person to whom this Part applies, matters to be taken into account by the Board include-
  - (a) the wishes of that person, so far as they can be ascertained; and
  - (b) the consequences to that person if the proposed treatment is not carried out; and
  - (c) any alternative treatment available to that person; and
  - (d) whether the proposed treatment can be postponed on the ground that better treatment may become available and whether that person is likely to become capable of consenting to the treatment; and
  - (e) in the case of transplantation of tissue, the relationship between the 2 persons concerned; and
  - (f) any other matters prescribed by the regulations.

### **Australian Capital Territory**

The ACT Government does not support non-therapeutic, forced sterilisation on young girls and women with disabilities. The Canberra Hospital does, however, recognise the need where these

young girls and women become extremely distressed with the management of their menstrual cycle, to implement appropriate medication management that may inhibit or decrease their symptoms related to menstruation, with their consent or their carers' consent.

The ACT *Power of Attorney Act 2006* can appoint power of attorney to make medical decisions in the event that an individual loses capacity. Under this Act, an adult can grant another adult an enduring power of attorney to make decisions for a person with impaired decision-making capacity, as defined by this Act. Individuals to whom a power of attorney has been granted may not exercise power in relation to 'special health care matters'. Special health care matters are defined by Section 37 of this Act to be:

- (a) removal of non-regenerative tissue from the principal while alive for donation to someone else;
- (b) sterilisation of the principal if the principal is, or is reasonably likely to be, fertile;
- (c) termination of the principal's pregnancy;
- (d) participation in medical research or experimental health care;
- (e) treatment for mental illness;
- (f) electroconvulsive therapy or psychiatric surgery;
- (g) health care prescribed by regulation.

If a person cannot give their own consent (i.e. if they have an 'impaired decision making ability') for a prescribed treatment, an ACT Civil and Administrative Tribunal (ACAT) order is required. The law applicable to ACT adult residents unable to provide informed medical consent is the *Guardianship and Management of Property Act 1991*. Under this Act, sterilisations and other matters are referred to as prescribed medical procedures and such medical determinations may only be made by the ACAT. ACAT is required to give consideration to the following:

- (a) the procedure is otherwise lawful; and
- (b) the person is not competent to give consent and is not likely to become competent in the foreseeable future; and
- (c) The procedure would be in the person's best interests; and
- (d) The person, the guardian and any other person whom the ACAT considers should have notice of the proposed procedure are aware of the application for consent.

In addition, for prescribed medical procedures including sterilisation, legislation requires that:

1. The ACAT must appoint the person's guardian, or the public advocate or some other independent person, to represent the person in relation to the hearing relating to the consent.
2. In deciding whether a particular procedure would be in the person's best interests, the matters that the ACAT must take into account include:
  - (a) The wishes of the person, so far as they can be ascertained; and
  - (b) What would happen if it were not carried out; and
  - (c) What alternative treatments are available; and
  - (d) Whether it can be postponed because better treatments may become available; and
  - (e) For a transplantation of tissue-the relationship between the 2 people and other matters.

Compulsory treatment and intervention can only be used when the legislation is satisfied either under the *Crimes Act* or the *Mental Health (Treatment and Care) Act*. Safeguards include criteria-based treatment and intervention, the capacity to review decisions, transparency in decision making,

and the statutory requirement for periodic review, procedural fairness mechanisms, and the person to whom the compulsory measures are taken being afforded representation.

Oversight agencies, such as the Public Advocate, also play a role in educating the community about special medical procedures and the legal requirements that must be followed, and about the rights of all girls and women, particularly girls and women who are unable to provide informed medical consent.

## **Northern Territory**

In the NT sterilisation procedures are governed by two separate systems; one for adults and one for children.

### **Adults**

NT legislation does allow for sterilisation to be carried out however only in a situation where the consent of the court is obtained.

Section 21(2) of the *Adult Guardianship Act* (NT) provides that a medical practitioner or dentist must not carry out a 'major medical procedure' on a 'represented person' unless the consent of the court has been obtained.

A 'represented person' is an adult in respect of whom an adult guardianship order is in effect. An adult guardianship order is only made under section 15 of the *Adult Guardianship Act* if the court is satisfied the person is under an intellectual disability and in need of an adult guardian.

Medical procedures relating to contraception or the termination of a pregnancy, are defined as 'major medical procedures' under section 21(4)(b) of the *Adult Guardianship Act*.

Section 21(8) of the *Adult Guardianship Act* provides that the court must be satisfied that the sterilisation procedure would be in 'the best interests' of the represented person before making the order. The currently used 'best interest' test is the common law test formulated by the Family Court in *Marion's Case*. Under section 21(8) if the court is satisfied on hearing an application under this section that it would be in the best interest of the represented person, it may, by order, consent to the major medical procedure.

The Court, in considering whether to make an order for a major medical procedure to be undertaken, will take into account the best interests of the adult. The court must also ascertain the wishes of the represented person as far as is reasonably possible (section 21(6)). Section 21(7) of the *Adult Guardianship Act* provides that, subject to section 21(8)- the 'best interest' test, if the court is satisfied that the represented person understands the nature of the proposed major medical procedure and is capable of giving or refusing consent to that procedure, the court shall give effect to the represented person's wishes.

### **Children**

Where a child is incapable of giving consent (due to an intellectual disability or immaturity), the NT follows the common law as laid down by the HCA in *Marion's Case*. Only the Family Court may give consent for a child to undergo sterilisation for non-therapeutic purposes (i.e. otherwise than as a by-product of surgery appropriately carried out to treat a malfunction or disease).

### **Emergencies**

Under the *Emergency Medical Operations Act* (NT) there is no need for authorisation if a medical practitioner believes that waiting for authorisation, to carry out the procedure from the courts,

would be harmful to the patient or result in the death of the patient. Similarly the *Adult Guardianship Act* provides that section 21 does not apply in respect of any medical or dental procedure carried out on any person in an emergency where the medical or dental procedure appears necessary to save the life of that person.

It is noted that:

- Section 60 of the *Mental Health and Related Services Act* (NT) prohibits sterilisation as a treatment for those suffering from a mental illness or mental disturbance.
- Section 64 of the *Mental Health and Related Services Act* provides that a major medical procedure cannot be performed on a person who is an involuntary patient or subject to a community management order unless the Mental Health Review Tribunal has given its approval. Separate legal representation is also provided at no cost to a person who appears before the Tribunal.

### **3. Please provide details of any actions to sanction medical staff carrying out illegal non-therapeutic, forced sterilisations of girls and women with disabilities, and where available, the results of any investigation and judicial or other inquiries carried out in relation to such cases. If no inquiries have been made, or if they have been inconclusive, please explain why.**

The Australian Government is not aware of any recent evidence concerning sterilisations of girls or women with disabilities that have been carried out in contravention of Australian law. Also, the 2006 SCAG review concluded that sterilisations of children with an intellectual disability had declined significantly in Australia since 1997. If such evidence were presented the Australian Government would be very concerned.

#### ***Current Avenues for Sanction***

Under Australian law generally, there are a range of regulations and protections to ensure that medical practitioners are appropriately sanctioned in the event of a medical procedure being carried out in a manner that contravenes the law or disregards the rights of patients

#### **Sanctions of Medical Practitioners**

Medical practitioners in Australia are required to be registered by the Medical Board of Australia (MBA), in accordance with the *Health Practitioner Regulation National Law Act 2009* (National Law) as adopted in each State or Territory. The MBA is responsible for regulating the practice of the medical profession by registering practitioners, developing professional practice standards, overseeing the assessment of the skills of overseas trained practitioners and managing notifications and complaints against practitioners. The MBA is supported in its role by the Australian Health Practitioner Regulation Agency (AHPRA), an independent statutory agency.

The MBA has issued a code of conduct for doctors in Australia, entitled *Good Medical Practice: A Code of Conduct for Doctors in Australia*. This code articulates the ethical and professional conduct expected of all practitioners and has been developed to be consistent with the *Declaration of Geneva and the International code of Medical Ethics*, issued by the World Medical Association.

Where a medical practitioner's behaviour departs from the code of conduct, the MBA may take action against the practitioner. This action may take the form of cancelling the practitioner's registration, cautioning the practitioner, requiring an undertaking, placing conditions on the practitioner's registration or referring the matter to the health complaints entity in the relevant State or Territory. Where the MBA considers that a practitioner's conduct constitutes professional misconduct, the matter must be referred to a responsible tribunal in the relevant State or Territory. A tribunal may impose a range of sanctions, including suspension or cancellation of the practitioner's registration.

All tribunal outcomes are made available to the public online at:

<<http://www.ahpra.gov.au/Notifications-and-Outcomes/Hearing-Decisions.aspx>>

Members of the public may report concerns about a medical practitioner's professional conduct to AHPRA. In addition, other health professionals regulated by the National Law, and employers of medical practitioners, are required to report a reasonable belief that a medical practitioner has placed the public at risk by practising in a way that significantly departs from accepted professional standards. The exception to this is that health professionals in WA are not bound by mandatory notification if the health professional in question is a client or patient, however they may still volunteer the information.

The notification process can be found in full detail online at:

<<http://www.ahpra.gov.au/Notifications-and-Outcomes/Notification-Process.aspx>>.

### **Medicare Australia and inappropriate practice**

The Australian Government's Department of Human Services' (DHS) objective is to make sure payment of Medicare benefits is correctly made for services properly rendered. DHS operates a Health Provider Compliance function. The Health Provider Compliance function is responsible for preventing, detecting and investigating fraud and inappropriate practice.

Health Provider Compliance works with the health industry to:

- ensure the correct benefits are claimed for properly rendered services, and
- prevent and detect fraud and inappropriate practice with respect to claiming of benefits.

Health Provider Compliance applies a balance of education and compliance strategies to meet the requirements for the *Health Insurance Act 1973*, *National Health Act 1953*, and the *Medicare Australia Act 1973*.

If DHS became aware of a claim made for a service that was ineligible for payment of benefits due to an unlawful act, then DHS may take the following actions:

- recover incorrectly paid benefits
- request the Director of Professional Services Review to review the provision of services under Medicare by the practitioner
- refer the matter to Australian Health Practitioner Regulation Agency (AHPRA), and
- refer the matter to the State or Australian Federal police in the relevant jurisdiction.



## **State and Territory Sanctions**

In addition, in each of the States and Territories there are a number of schemes and systems which protect the rights of individuals by imposing sanctions where medical practitioners act inappropriately.

For example, the national Health Practitioner Registration and Accreditation Scheme (which is enacted in Victoria through the *Health Practitioner National Law (Victoria) Act 2009* provides the means for sanctions against registered health practitioners who act illegally or unprofessionally. The Victorian Government does not know if any procedures involving the sterilisation of girls and women with disabilities have been the subject of investigations or actions by the scheme.

## **4. Please provide details of any actions to ensure that reparation, including compensation and rehabilitation, is provided to those girls and women with disabilities who may have been forcibly sterilised.**

As noted above, Australian Government is not aware of any recent evidence concerning sterilisations of girls or women with disabilities that have been carried out in contravention of Australian law. However, were such allegations to be proven, generally there are a number of avenues for redress under Australian law.

### ***Current Avenues for Redress***

Compensation can generally be sought in Australia through four different avenues. Victims can:

- receive a court-ordered payment from an offender as part of a criminal penalty after conviction, or
- issue proceedings for civil damages.

In the current context, under Commonwealth, State and Territory laws there are a range of statutory and common-law criminal and civil offences which deal with unauthorised medical procedures and medical negligence.<sup>5</sup>

In Victoria, for example, the *Guardianship and Administration Act 1986* (VIC) provides quite severe penalties, including up to two years imprisonment and 240 penalty units (one penalty unit is \$122.14), for any medical practitioner who carries out a special procedure without having obtained the proper consent.

At the request of the previous Attorney-General, the Attorney-General's Department is considering options for reform of the Australian legal framework around sterilisation procedures. The creation of sanctions for unauthorised or inappropriate sterilisations, and options for redress girls and women with disabilities who may have been sterilised without their informed consent, or the consent of a court or tribunal, is an issue under consideration. These issues will be raised these issues during discussions with States and Territories.

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<sup>5</sup> See for example legislation including but not limited to: the *Criminal Code Act 1995* (Cth), the *Civil Liability Act 2002* (NSW), and the *Wrongs Act 1958* (VIC). See also common-law authorities including but not limited to *Rogers v Whitaker* (1992) 175 CLR 479, and *Chappel v Hart* [1998] HCA 55.

## **5. Please provide details of any actions to ensure that informed consent requirements are adequately implemented for all medical interventions with regard to children and persons with disabilities.**

### *Informed Consent*

There are a number of resources available in Australia to ensure that informed consent requirements are adequately implemented for medical interventions.

The discussions of the HCA in *Marion's Case* regarding the limits of parental authority, consent and medical interventions for children with disabilities have been considered and referenced by judicial officers in both sterilisation and other (non-sterilisation) cases to assist in their assessment of the consent requirements for medical interventions more broadly.<sup>6</sup> In many cases the appointment, at the Court's discretion, of an independent advocate also helps to ensure that the interests of children or adults who cannot provide informed consent are directly represented alongside the wishes of their families or carers.

The States and Territories have also developed statutory frameworks to ensure that an individual's wishes are a primary consideration in decisions made about their health.

In the State of Victoria, for example, the *Guardianship and Administration Act 1986* expressly provides that it is the intent of the Victorian Parliament that any decision or action taken under that Act is the least restrictive of a person's freedom of decision and action; that the best interests of the person are promoted; and the wishes of the person are given effect to wherever possible.

To give effect to these principles Victorian Office of the Public Advocate (OPA) publishes a Practice Guideline to assist OPA staff in dealing with applications for special procedures. The Guideline sets out the legal framework surrounding special procedures and the evidentiary requirements to establish the capacity of the person, the medical need for the procedure, what less restrictive alternatives are available and have been tried, the wishes of the person and what is in their best interests.

In addition, both the Victorian Civil and Administrative Tribunal (VCAT) and OPA as public authorities are required to give proper consideration to and act compatibly with the relevant human rights set out in the *Charter of Human Rights and Responsibilities Act 2006* (VIC). This means when considering applications for special procedures OPA and VCAT must have regard to:

- Recognition and equality before the law as this right deals with discrimination.
- Protection from torture, and cruel, inhuman or degrading treatment as this deals with consent to medical treatment.
- Protection of families may be relevant to a person being able to have a family.
- Right to a fair hearing - ensuring that the person with the disability is properly heard at any hearing about the special procedure.

A number of Australian governments also produce guidance materials for non-legal practitioners. The Queensland Government for example, publishes *Health Policy Statements* advising medical

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<sup>6</sup> See for example *Re: Baby D (No. 2)* [2011] FamCA 176

professionals and the public of their rights and obligations - this includes the operation of informed consent requirements in relation to children and persons with disabilities.<sup>7</sup>

In addition, there is also a wide variety of relevant guidance materials prepared by advisory groups, professional associations and non-government organisations, all of which assist in educating relevant professionals about the informed consent requirements so that they are adequately implemented.

### **The Australian Medical Association (AMA)**

As the peak organisation representing the medical profession, the AMA develops policy solutions and provides responses to a broad range of health and medical issues of ongoing importance to Australia. The AMA has produced guidelines on a number of topics that stress the importance of informed consent, including but not limited to the *AMA Code of Ethics - 2004 (Editorially Revised 2006)*, and Guidelines on topics including Informed Financial Consent and Human Genetic Issues.<sup>8</sup>

### ***Guidance on Sterilisation***

In addition to resources which assist with upholding informed consent requirements generally, there are also a number of resources to assist persons involved in applications for sterilisation.

### **The Family Law Rules**

Guidance for judges in the Family Court can be found in the *Family Law Rules 2004* which make special provision in relation to applications for authorisation of a medical procedure. In particular, Rule 4.09(1) provides that 'if a Medical Procedure Application is filed, evidence must be given to satisfy the court that the proposed medical procedure is in the best interests of the child.'

Further, Rule 4.09(2) requires, under the heading 'Evidence supporting application,' that the evidence a court should consider in such cases:

'...must include evidence from a medical, psychological or other relevant expert witness that establishes the following:

- (a) the exact nature and purpose of the proposed medical procedure;
- (b) the particular condition of the child for which the procedure is required;
- (c) the likely long-term physical, social and psychological effects on the child:
  - i. if the procedure is carried out; and
  - ii. if the procedure is not carried out;
- (d) the nature and degree of any risk to the child from the procedure;
- (e) if alternative and less invasive treatment is available -the reason the procedure is recommended instead of the alternative treatments;

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<sup>7</sup> For a copy see the Queensland Health website at <http://www.health.qld.gov.au/consent/documents/14025.pdf>.

<sup>8</sup> For more information see the AMA website- <http://ama.com.au>.

- (f) that the procedure is necessary for the welfare of the child;
- (g) if the child is capable of making an informed decision about the procedure -whether the child agrees to the procedure;
- (h) if the child is incapable of making an informed decision about the procedure-that the child:
  - i. is currently incapable of making an informed decision; and
  - ii. is unlikely to develop sufficiently to be able to make an informed decision within the time in which the procedure should be carried out, or within the foreseeable future;
- (i) whether the child's parents or carer agree to the procedure.'

Together with the HCA's decision in *Marion's Case*, these Rules provide guidance as to the factors the Family Court should consider when determining whether it is in the best interests of a child to authorise the performance of a sterilisation procedure on that child.

### **The Australian Guardianship and Administration Council (AGAC)**

The AGAC provides a national forum for State and Territory agencies that protect adults with a decision-making disability through adult guardianship and administration.

In May 2009, the AGAC issued the *Protocol for Special Medical Procedures (Sterilisation)*, which assists the various guardianship tribunals to exercise their decision-making power to promote consistency across jurisdictions when dealing with an application for the sterilisation of a person.

The Protocol, which is periodically reviewed, explains that:

- 1.1 'In all States and Territories of Australia, sterilisation is considered to be such an invasive and irreversible procedure, that where a person cannot give a valid consent to the procedure, an entity such as the Family Court, a state supreme court or guardianship tribunal is the only authority that can provide consent. Further, because of the invasive and irreversible nature of the procedure, the law in all States and Territories provides that, unlike many other medical procedures, a person's normal substitute decision- maker for medical and dental treatment cannot make the decision about sterilisation.
- 1.2 For adults with impaired decision-making abilities, consent to the procedure was, and is, given or refused by the State or Territory tribunals that deal with capacity, guardianship and administration issues.
- 1.3 For children, the question of sterilisation is a matter for the Family Court of Australia, however the tribunals of four States also have this jurisdiction.

The Protocol specifically notes that it is intended to assist all persons including 'applicants, potential applicants, relevant professionals and members of the public in understanding the decision-making process and what is required of them in bringing, or objecting to an application to sterilise a person.'<sup>9</sup>

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<sup>9</sup> A copy of the Protocol is available on the AGAC website at:  
<[http://www.agac.org.au/images/stories/agac\\_sterilisation\\_protocol\\_30\\_mar\\_09.pdf](http://www.agac.org.au/images/stories/agac_sterilisation_protocol_30_mar_09.pdf)>

## **RANZCOG Guidelines**

The Royal Australian and New Zealand College of Obstetrics and Gynaecology (RANZCOG), whose primary role is to train and accredit doctors in the specialities of obstetrics and gynaecology, have produced guidelines on '*Sterilisation procedures for women with an intellectual disability*' (C-Gyn 10).

The RANZCOG guidelines state the following:

- In addressing the issues of fertility control for women with an intellectual disability, the least restrictive option and approaches which are similar to those one would consider for women of the same age but without intellectual disability, are the most appropriate.
- Reversible methods such as long acting reversible contraceptive implants (e.g. Implanon or Mirena) should be considered in preference to irreversible surgical options.
- The administration of treatment to a woman with intellectual disabilities must be in accordance with the current law and guardianship provisions of the relevant jurisdictions.<sup>10</sup>

## ***Guidance on the Rights of Patients***

The Australian jurisdictions also have a detailed system that sets out the rights of health care patients regardless of the medical issue they are experiencing.

## **The Australian Charter of Healthcare Rights**

The Australian Commission on Safety and Quality in Health Care (the Health Care Commission) identified a need for a national Charter of patient rights in 2007, in order to build trust in the healthcare system and assist the development of mature and balanced relationships between patients and providers based on a shared understanding of their rights and responsibilities. Following extensive consultation, the Health Care Commission developed the *Australian Charter of Healthcare Rights* (the Charter). The Charter was endorsed by Australian Health Ministers in July 2008.<sup>11</sup>

The purpose of the Charter is to provide information about the rights of patients and consumers to underpin the provision of safe and high quality care, and to support a shared understanding of the rights of people receiving care. The Charter applies in all health care settings including public hospitals, general practice and other ambulatory care environments.

Although each State and Territory has existing patient charters, the national Charter addresses jurisdictional variations and is uniformly applicable in all settings in which healthcare is delivered.

The Charter specifies the key rights of patients and consumers when seeking or receiving health care services. These are: safety, respect, communication, participation, privacy, comment and access. Briefly, the key rights of respect, communication and participation explicitly state that patients have the right to be:

- shown respect, dignity and consideration. The care provided shows respect to the patient, their culture, beliefs, values and personal characteristics

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<sup>10</sup> A copy of these guidelines is available online at <http://www.ranzcog.edu.au/publications/statements>.

<sup>11</sup> A copy of a supporting document developed by the Health Care Commission outlining the roles and responsibilities under the Charter is at *Attachment 1*.

- informed about services, treatment, options and costs in a clear and open way. The patient receives open, timely and appropriate communication about their health care in a way that they can understand, and
- included in decisions and choices about their care.

Under the *National Health Reform Agreement*, signed on 2 August 2011, all States and Territories have agreed the following requirements in relation to patients' rights:

- to prepare and distribute a Public Patients' Hospital Charter (the Charter), in appropriate community languages to users of public hospital services
- to maintain complaints bodies independent of the public hospital system to resolve complaints made by eligible persons about the provision of public hospital services received by them
- to develop the Charter in appropriate community languages and forms to ensure it is accessible to people with disabilities and from non-English speaking backgrounds
- to develop and implement strategies for distributing the Charter to public hospital service users and carers
- to adhere to the Charter
- the Charter will be promoted and made publicly available whenever public hospital services are provided, and
- the Charter will set out a statement of the rights and responsibilities of consumers and public hospitals in the provision of public hospital services in States and the mechanisms available for user participation in public hospital services.<sup>12</sup>

## **6. What measures are being taken to ensure the enjoyment of the right to health of girls and women with disabilities?**

The Australian Government has a strong commitment to initiatives that improve the health and wellbeing of people with disabilities, including girls and women, both domestically and internationally. The following initiatives, whilst more broadly targeted at improving the enjoyment of all rights of persons with disabilities, contribute significantly to the enjoyment of the right to health of girls and women with disabilities.

### ***The National Disability Strategy***

Australia has developed a comprehensive national action framework that aims to improve the lives of people with disability, promote participation, and create a more inclusive society. The National Disability Strategy 2010-2020 (the NDS) was launched by the Australian Government on 18 March 2011. This represents the first time in Australia's history that all levels of governments have committed to a unified, national approach to improving the lives of people with disability, their families and carers.

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<sup>12</sup> Attachment 2 gives details of Australian and state and territory specific charters of health care rights with specific information in relation to informed consent for care/treatment.

The NDS's ten-year framework will guide public policy across governments and aims to bring about changes to all mainstream services and programs, as well as community infrastructure, to ensure they are accessible and responsive to the needs of people with disability. This change is important to ensure that people with disability have the same opportunities as other Australians - a quality education, good health, economic security, a job where possible, access to buildings and transport, and strong social networks and supports. The NDS will also be an important mechanism to ensure that the principles underpinning the CRPD are incorporated into policies, services and programs affecting people with disability, their families and carers.

The NDS acknowledges that people with a long-term disability are among the most disadvantaged and invisible groups in our community, with comparatively poor health status and a health system that often fails to meet their needs. This includes people with an intellectual disability, as well as people with other long-term physical and mental conditions, whether present at birth or acquired later in life. These poorer health outcomes include aspects of health that are unrelated to the specific health conditions associated with their disability.

Consequently, one of the central outcomes of the NDS is to ensure that people with disability attain the highest possible health and wellbeing outcomes throughout their lives. The NDS commits to a range of Areas for Future Action designed to achieve this outcome. These action areas focus on:

- improving the interface between disability services and key health services in local communities
- strengthening the continuity and coordination of care
- addressing issues specific to people with disability as part of key national health strategies, such as dental, nutrition, mental health, and sexual and reproductive health programs, and
- ensuring informal and supported decision makers are part of the preventive, diagnostic and treatment programs where appropriate, always ensuring the rights of the individual are respected and protected.

While the NDS aims to improve the lives of all Australians with disability, it recognises that people with disability have specific needs based on their personal circumstances, including the type and level of support required, gender, age, education, sexuality, and ethnic or cultural background. In particular, it recognises that gender can significantly impact on the experience of disability and women and girls with disability often face different challenges by reason of their gender.<sup>13</sup>

### ***National Women's Health Policy 2010***

The National Women's Health Policy 2010 (the Policy), released in December 2010, aims to provide a framework to improve the health and wellbeing of all women in Australia, especially those at the greatest risk of poor health, through addressing particular health issues, focusing on the social determinants of health inequities and encouraging the health system to be more responsive to women.

The Policy was developed through an extensive consultation process with a wide range of key women organisations, including Women With Disabilities Australia (WWDA), the peak organisation for women with all types of disabilities in Australia.

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<sup>13</sup> More information about the NDS is available at: <http://www.fahcsia.gov.au/saJdisability/progserv/govtint/Pages/nds.aspx>.

The Policy identifies women with disabilities as being one of the groups which are at greater risk of poor health as health is determined by a broad range of social, cultural, environmental, economic factors, as well as the genetic and biological factors.

The Policy seeks to understand health within its social context and is based on a gendered approach that is inclusive of a social view of health, and accounts for the diversity in women's experiences. The social model of health acknowledges the complex ways that the context of a woman's life—including her gender, age, socio-economic status, ethnicity, sexuality, disability and geography—might shape her health outcomes; access to health care; experiences of health, wellbeing and illness; and even her death. Addressing these social determinants is a fundamental step towards reducing health inequalities.

### ***National Health Reform***

To ensure that the health system is more responsive to the needs of individuals and local communities, the Australian Government is establishing a coordinating network of primary health care organisations called Medicare Locals. Medicare Locals comprise a major component of the Government's National Health Reform agenda, and are critical to supporting and driving improvements in primary health care for both patients and health care providers.

Medicare Locals will provide all patients with increased access to information regarding services available in their local area and make it easier for patients to navigate their local health care system.

Medicare Locals will support primary health care professionals and organisations to identify and address local health care needs, and improve the delivery of integrated primary health care services.

As they develop, each Medicare Local will develop plans for its particular population and its health needs, including preventive health activities. Primary health care providers will work with Medicare Locals to incorporate women's health into the implementation of initiatives to improve the prevention and management of disease in general practice and primary health care.

The Australian Government also supports women's acute care health services by contributing to the funding of Australia's public hospitals which are administered by the State and Territory Governments. These public hospitals include eleven large hospitals dedicated to the provision of services to women and/or children.

The reforms, agreed to by the Council of Australian Governments (COAG) in February, were finalised on 2 August 2011. This Agreement will invest an extra \$19.8 billion in public hospitals through to 2019-20, rising to a total extra \$175 billion to 2029-30 matched by tough national standards. In this way, the Agreement will benefit women by funding the provision of better public hospital services, including those delivered by the eleven dedicated women and children's hospitals.

Further opportunities for implementing the *National Women's Health Policy 2010* will be considered in the context of National Health Reform.

### ***The National Disability Insurance Scheme (NDIS)***

On 10 August 2011 the Prime Minister released the Productivity Commission's<sup>14</sup> final report into care and support for people with disability. The Government asked the Productivity Commission to

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<sup>14</sup> The Productivity Commission is the Australian Government's independent research and advisory body on a range of economic, social and environmental issues affecting the welfare of Australians. Its role, expressed simply, is to help governments make better policies in the long term interest of the Australian community. More information about the Productivity Commission is available at: <http://www.pc.gov.au/>.



examine reform of disability support services because the Australian Government believes that the system we have today is not delivering the kind of care and support Australians expect for people with disability.

The Productivity Commission has recommended a NDIS that would entitle all Australians to support in the event of significant disability. The Productivity Commission has also recommended a separate National Injury Insurance Scheme (NIIS) to provide no-fault insurance for anyone who suffers a catastrophic injury. The Productivity Commission made clear in its report that there is a lot of work ahead to prepare for a trial of a scheme in 2014.

The Australian Government shares the vision of the Productivity Commission for a system that provides people with disability with the care and support they need over the course of their lifetime. The Commonwealth Government has started work- with States and Territories that are principally responsible for funding and delivering disability support services -to fundamentally reform disability care and support. Work is underway to lay the foundations which are essential for the launch of a National Disability Insurance Scheme. This includes working with the States and Territories to:

- Develop common assessment tools, so people's eligibility for support can be assessed fairly and consistently, based on their level of need.
- Put in place service and quality standards, so that people with disability can expect high quality support irrespective of what disability they have or how they acquired it.
- Build workforce capacity so we have more trained staff to support people with disabilities.<sup>15</sup>

### ***The National Strategy for Young Australians***

The *National Strategy for Young Australians* sets out the Australian Government's vision for young people 'to grow up safe, healthy, happy and resilient and to have the opportunities and skills they need to learn, work, engage in community life and influence decisions that affect them.' The *National Strategy for Young Australians* will help guide future Australian Government policies and initiatives for young people, including consideration of groups at risk such as young people with a disability, those with mental health issues and young people exiting care.

### ***Specialised Services***

The Commonwealth, State and Territory governments work together to deliver a wide range of specialist disability services for Australians, including girls and women, through the *National Disability Agreement* (NDA).

Under the NDA, the Commonwealth Government has responsibility for employment and income support payments such as Disability Support Pension. Other specialist services are the responsibility of State and Territory governments. Specialist disability services are accessed by Australian women and men on an equal basis, and are based on functional needs rather than diagnosis.

From 1 January 2009 to 30 June 2015, the Commonwealth Government will be providing around \$7.6 billion in funding to the State and Territory governments for increased and improved specialist

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<sup>15</sup> More information about the NDIS and NHS is available at:  
<http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/ndis.aspx>.

disability services such as supported accommodation, targeted support and respite. The Agreement means that in 2014-2015, the Commonwealth Government's contribution will be around \$1.4 billion, compared to \$620 million in 2006-07.

### ***Recognition and Support for Carers***

The Australian Government recognises the very important role played by Australians who are the carers of girls and women with disabilities. Following public consultation, in August 2011 the Australian Government launched, the National Carer Strategy (NCS). The NCS represents the Australian Government's long term commitment to carers. It will guide future reforms, and it builds on reforms the Government is already delivering to better support carers.

There is wide appreciation in the community that the majority of carers who support girls and women with disabilities are women. The Australian Government has adopted several recent initiatives to ensure improved support to carers; and hence to ensure improved enjoyment of the right to health of girls and women with disabilities.

The Australian Government has also recently put in place legislation that formally recognises the role of carers, *Carer Recognition Act 2010*.

### ***Support for Non-Government Organisations for People with Disability***

The Australian Government is committed to encouraging participation in and working with non-governmental organisations, peak bodies and associations including those that have a focus on people with disability. These peak bodies represent many types of disabilities, as well as the interests of particular demographic groups of people with disability, for example children and women.

These bodies consult with people with disability and draw on the resources of their member organisations to provide the Australian Government with the perspective of the people with disability they represent. Engagement with these bodies is essential to ensuring that people with disability are consulted and involved in decision-making processes concerning issues relating to people with disability. This includes health issues.

Government support for non-government organisations, whilst more broadly targeted, contributes significantly to the enjoyment of the right to health of girls and women with disabilities.

### **The Annual Non-Government Organisation (NGO) Forum**

Recognising the important role played by non-governmental organisations and as part of Australia's Human Rights Framework, an Australian Government NGO Forum on Human Rights is hosted annually by the Commonwealth Attorney-General and the Minister for Foreign Affairs and Trade. The NGO Forum is a key opportunity for comprehensive dialogue on a range of domestic and international human rights issues, including health issues, between the Australian Government and civil society.

### **Consultation with women with disabilities on issues that affect them**

The Australian Government provides funds WWDA, the peak body representing women with disabilities in Australia. WWDA is funded to contribute to government policies about disability issues affecting Australian families and communities, to carry information between the Government and the community on social policy issues and to represent the views of its constituents.

WWDA's work is grounded in a human rights based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights. This rights based approach recognises that equal treatment, equal opportunity, and non-discrimination provide for inclusive opportunities for women and girls with disabilities in society.

WWDA also seeks to create greater awareness among governments and other relevant institutions of their obligations to fulfil, respect, protect and promote human rights and to support and empower women with disabilities, both individually and collectively, to claim their rights.

The Australian Government also funds six National Women's Alliances, which work collaboratively to provide informed and representative advice to government on policy development and implementation relevant to the diverse views and circumstances of women. WWDA is an active member organisation of both the Equality Rights Alliance and the Economic Security for Women Alliance

### ***State and Territory Examples of Measures to Ensure the Right to Health***

Provided below is an example of some of the wide range of projects and programs being implemented by State and Territory Governments that also aim to improve the health and wellbeing of people with disabilities, including girls and women. This information is intended to supplement the information about the federal initiatives listed above, and provide a 'case study' of the important work being done by State and Territory Governments to advance and protect the human rights of people with disabilities.

#### **Victoria**

The Disability Services Division (DSD), of the Victorian Department of Human Services is working to increase the capacity of both the disability service and the family violence sectors to respond to family violence for women with a disability. This includes the *Disability and Family Violence Crisis Response* initiative which will assist women with a disability experiencing family violence who may require immediate disability support to access specialist family violence services while exploring longer term housing and support options. Short term funding will be available to meet immediate needs where required.

In addition, DSD has been working with the Department of Health to improve the outcomes for people with a disability. In particular there has been a focus on strengthening the communication and working relationship between regional Disability Services and Health Services. The aim is to ensure that people with a disability are assisted via pathways to the most suitable forms of health and disability support.

The first Victorian population health survey in relation to people with an intellectual disability report was released in October 2011. This report represents a significant step forward in understanding the health and well being of Victorians with an intellectual disability. Its findings will better inform decisions about the priorities and health interventions aimed at this vulnerable group.

A key finding from the report was that Victorian women with an intellectual disability were less likely to have mammograms and Pap Tests, compared with women in the general population. To address this issue, a grant has been made available to the Cancer Council of Victoria to increase cancer screening participation of women with an intellectual disability.

In addition to these specific programs, there are external organisations that have a role in monitoring disability service providers to protect and promote the rights of people with a disability. They include:

- Victorian Public Advocate, Including the Community Visitors Program.
- Disability Services Commissioner (independent complaints body).
- Office of the Senior Practitioner (monitoring restrictive interventions).
- National abuse and neglect hotline.

## Appendix 4: Terms of Reference

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On 20 September 2012 the Senate referred the matter of involuntary or coerced sterilisation of people with disabilities in Australia to the Senate Community Affairs Committee for inquiry and report by 24 April 2013.

The **Terms of Reference** for the Inquiry are:

**1. The involuntary or coerced sterilisation of people with disabilities in Australia, including:**

- (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;
- (b) the prevalence of these sterilisation practices and how they are recorded across different state and territory jurisdictions;
- (c) the different legal, regulatory and policy frameworks and practices across the Commonwealth, states and territories, and action to date on the harmonisation of regimes;
- (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;
- (e) the impacts of sterilisation of people with disabilities;
- (f) Australia's compliance with its international obligations as they apply to sterilisation of people with disabilities;
- (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; and

(h) any other related matters.

**2. Current practices and policies relating to the involuntary or coerced sterilisation of intersex people, including:**

(a) sexual health and reproductive issues; and

(b) the impacts on intersex people.