

# **SUBMISSION TO THE SENATE COMMITTEE INQUIRY ON THE INVOLUNTARY OR COERCED STERILISATION OF PEOPLE WITH DISABILITIES IN AUSTRALIA**

Susan Hayes  
Professor of Behavioural Sciences in Medicine,  
Sydney Medical School,  
University of Sydney, NSW 2006

## **Terms of reference**

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.

## **Background to this submission**

I am a registered forensic psychologist (AHPRA) and Professor of Behavioural Sciences in Medicine at the Sydney Medical School in the University of Sydney. I am a Fellow of the International Association for the Scientific Study of Intellectual and Developmental Disabilities, member of the Australasian Society for the Study of Intellectual Disability, member of the Australian Psychological Society, member of the American Association on Intellectual and Developmental Disabilities, member of the Australian and New Zealand Association of Psychiatry, Psychology and Law, and member of Australian Academy of Forensic Sciences.

Over the past two years I have assisted WHO to prepare a draft policy on involuntary sterilisation of people with disabilities, which has now been broadened to include involuntary sterilisation procedures for non-disabled members of the population as well. The policy is still under development.

In my practice as a forensic psychologist I have been asked to give an expert opinion regarding a proposal for a procedure which will result in the sterilisation of a person with a disability in over 15 cases.

## **Sterilisation of people with disabilities**

Involuntary or coerced sterilisation of people with intellectual or other disabilities has been conducted since the time that such medical procedures became available, and up until recent times in many countries including Western nations. Whilst the focus has been upon sterilisation of women and girls with disabilities, men and boys have also been the subject of such procedures, often with a eugenic aim.

## **Submissions related to the Terms of Reference**

### **(a) The types of sterilisation practices that are used, including treatments that prevent menstruation or reproduction, and exclusion or limitation of access to sexual health, contraceptive or family planning services**

Reproductive sterilisation is defined as “the process of rendering an individual incapable of sexual reproduction by castration, vasectomy, bilateral orchidectomy [removal of testes], salpingectomy [removal or destruction of a woman’s fallopian tubes], or hysterectomy” (<http://medical-dictionary.thefreedictionary.com/sterilization> Accessed 23 June 2011). Other possible techniques include endometrial ablation and bi-lateral oophorectomy. For females, contraception medication can be used to control fertility and in some instances, menstruation.

In the case of males, pharmaceutical limitations on fertility can be achieved through use of medication such as Depo-Provera and Androcur, which reduce male hormones, libido and fertility (Carlson, Taylor et al. 2000; Hayes 2002).

This inquiry focuses upon involuntary sterilisation, that is, where the individual undergoing the procedure has not given informed consent. A distinction has been drawn between “forced” sterilisation (meaning that the patient was unaware that she/he had been sterilised)

and “coerced” sterilisation (meaning that some form of pressure, often in the form of medical misinformation, threats of removal of children, or threats of withdrawal of social security benefits) was used to persuade the patient to undergo sterilisation (Commission on Security and Cooperation in Europe 2003). A further possibility is third party consent where consent to the procedure is given by a third party including a family member, guardian, court, review board or tribunal.

**(b) The prevalence of these sterilisation practices and how they are recorded across different state and territory jurisdictions**

The organisation Women with Disabilities Australia (WWDA) asserts that “anecdotal reports and health insurance statistics provide evidence that non-therapeutic sterilisation of girls with disabilities has occurred in greater numbers than officially reported” (Women with Disabilities Australia 2011).

During the preparation of this submission, no recent research could be located on the prevalence of sterilisation practices in the States and Territories of Australia. One study of Family Court and Guardianship Tribunal decisions took place in the 1990s (Brady 2001). Other publications relevant to the issue of prevalence can be found on the Human Rights and Equal Opportunity website and the information will not be summarised here.

Whilst there is a debate about prevalence and incidence, it appears that the numbers of sterilisation procedures where third party consent is given is very small, and the decisions are made in the light of extensive independent information presented to the body which makes the decision.

**(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**

No comments will be made about this area.

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

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

In my experience, most or all parties are scrupulous in taking steps to determine the wishes of the person with a disability. This may involve appointing a separate legal representative for the person, or obtaining an expert opinion from an appropriate professional, or both. Many professionals are commonly involved, and the process is transparent.

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

A similar process is employed to determine the 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**

Often the individual has a separate legal representative who then seeks an expert opinion about the individual's capacity to give free and informed consent and the impact of the proposed procedure on the individual's quality of life and best interests. In some cases a separate legal representative has not been appointed, and the process goes directly to an independent third party professional expert opinion. The Guardianship Tribunal, Supreme Court or Family Court may be involved, and each of these bodies can be assisted by a third party expert opinion as well as information from treating specialists.

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

There are some valid reasons why sterilisation of a person with a disability may be considered to be in their best interests, and indicated for therapeutic reasons although the individual may not be capable of giving informed consent. These reasons can include the following conditions that persist and endanger the health, or current or future well-being of the individual, despite other less restrictive interventions (e.g. education, training, behaviour management strategies, independent living skills programs, and pharmacological treatment) having been trialled:

- Addressing severe pain and physical discomfort such as cramps and excessively heavy bleeding which may be associated with menstruation;
- Ameliorating other medical conditions that might be affected by hormonal fluctuations, such as epilepsy;
- Addressing difficult or inappropriate social behaviours associated with menstruation, which may affect the individual's quality of life by preventing participation in community or educational activities during menstruation, and which may be particularly oppressive for the individual when menstruation occurs almost continuously;
- Interaction between medication for contraceptive reasons and other necessary medication;
- Evidence that contraceptive medication is affecting the growth of the individual or contributing to a decline in their health in other ways;
- Presence of other medical conditions which affect the health and well-being of the individual, such as endometriosis or cancer.

In some instances more major ethical issues concerning the best interests of the individual present themselves, for example, the case of a young man with an intellectual disability and a particularly damaging neurodegenerative disease where any offspring has a 50% chance of being similarly affected. The young man is indiscriminately sexually active, refuses to use contraception or take medication to affect his fertility, and does not inform his sexual partners of his condition or the risks to a foetus. All less restrictive alternatives (education, supervision, and social support) are tried, but short of virtual imprisonment, there is no impact on his behaviour. In this instance the sterilisation procedure would not be considered to be in the best interests of the individual, but rather in the best interests of his sexual partners (many of whom have an intellectual disability) or potential offspring. This example provides an instance of the complex ethical questions that need to be addressed.

The complex issues surrounding the concept of the best interests of the individual warrant processes of careful assessment of the individual and their capacity to consent, the alternative interventions available, and presentation of all the relevant information for legal or judicial review.

An independent expert usually evaluates the actions that will be in the best interests of the individual. Contrary to many expectations, the most difficult decisions can sometimes occur in cases of persons with moderate intellectual disabilities, or possibly mild intellectual disabilities existing with concurrent physical disabilities. The situation for an individual who is severely-profoundly intellectually disabled and who has 24-hour care and support may mean that menstrual management, for example, can be part of existing physical care, in addition to bathing, general hygiene and managing changes of continence pads or undergarments. Some case histories of assessments undertaken to provide an opinion as to (a) ability to consent, and (b) whether the procedure is in the best interests of the individual, are given in Appendix A.

In the case of individuals who are less dependent on care, their lives may be severely disrupted by menstrual issues. For example, they may not be able to attend their usual educational, social, work or recreational activities, and may become frustrated and angry when they are forced to remain at home because either appropriate levels of assistance are not available, or they cannot engage in a certain activity (such as swimming or dancing). This becomes particularly problematic when menstrual periods are heavy and prolonged, and cannot be managed by medication. Many people with disabilities are reliant upon a routine and can become distressed when their routine is disrupted.

The best interests test needs to take into account the current quality of life of the individual currently and in the future, including forecasts about their likely future situation once family support (if any) is no longer available to them. Clearly, all less restrictive alternatives should have been trialled and demonstrated to be ineffective, unworkable or not in the best interests of the individual.

### **(e) the impacts of sterilisation of people with disabilities**

In every instance in which I have provided an expert opinion, the effect of the proposed sterilisation procedure on the individual has been canvassed at length with the individual (where possible) and among family, carers, health professionals and legal representatives.

In some instances the individual has no concept of the procedure or indeed of sexuality or the functions of their body. Occasionally an individual is able to give an informed consent to the procedure and may wish to undergo a sterilisation procedure because he or she is aware that they will be unable to undertake a pregnancy or the care of a child. Some clients opt to undergo a procedure that will not only prevent conception but which will also prevent menstruation.

It is important that people with disabilities should not be prevented from undergoing a sterilisation procedure if that is their free and informed decision. Of equal importance is avoidance of extreme points of view that a sterilisation procedure should not be performed under any circumstances, based on a naive and ill-informed opinion that menstrual management can somehow be achieved without sterilisation. This is not always the case.

Furthermore, the issue of indefinite dependence on medication to control menstruation (where this is feasible) needs to be addressed; it may not be in the long-term best interests of the individual to be prescribed medication for four or five decades, in order to preserve their uterus and fertility when the plain fact of the matter is that their fertility will not be exercised, and a pregnancy and childbirth will never occur.

**(f) Australia's compliance with its international obligations as they apply to sterilisation of people with disabilities**

In my experience the rights of the individual to determine their own health care (where possible) are complied with, as are the procedures for assessing whether the individual is able to give free and informed consent currently or in the future. Furthermore, expert independent advice to the third party decision-maker where the individual is found to be incapable of giving consent.

**(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.***

It is not generally recognised that the prevalence of developmental disability is roughly the same as the prevalence of many other chronic health conditions which have higher public and medical research profiles, such as diabetes (2.2% of the population), hypertension (2%), depression (2.8%), heart disease (2%) and stroke (1.8%) (Australian Bureau of Statistics 2006).

A major barrier to availability and effectiveness of services and programs is the fact that people with disabilities may only be able to access health services through a carer or family member. For many reasons, carers and family members may not facilitate the person seeking out appropriate services; for example, they may not think that the person's sexuality is a relevant consideration, or cultural/language, religious factors may come into play. It is well established that women with disabilities seldom have Pap smear, or breast examinations, for example.

It is also well established that people with disabilities receive less than optimum health care. Accounting for the "hidden" nature of the health care needs of people with developmental disability is difficult (Lennox, Taylor et al. 2004). People with developmental disabilities may have difficulties in communicating with medical and health professionals and with the community at large; their families or carers may lack the skills and time to advocate for greater public awareness of the health inequalities faced by people with developmental disabilities. Generally, individuals with developmental disabilities have poorer uptake of health promotion and disease prevention activities (Ouellette-Kuntz 2005).

Therefore, all of these factors mean that it is less likely that people with disabilities will have equal access to health care especially in reproductive and sexual health. Health professional education needs to be greatly improved in these fields. In addition, there are few resources available to assist with developing individual programs to assist the individual and their

family/carers with managing these issues on a daily basis in practical terms in the home and community.

The dearth of accessible and appropriate services and programs does not necessarily directly relate to increased numbers of unnecessary sterilisation procedures, however.

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

Educational resources for these groups are difficult to locate and access. Medical schools' curricula pay little attention to inclusion of content about people with disabilities, and many medical schools do not have a discipline or sub-discipline to promote and take responsibility for ensuring that medical students have adequate or even minimal knowledge in the area. The same can be said for other health professions. For example, in the UK it is compulsory for intern psychologists to spend time working with people with disabilities, but this is not a requirement for registration in Australia. Most health professions can graduate their students and the students can gain registration without having any experience with disability generally or the specialist field of sexual and reproductive health. It is extremely difficult for guardians, carers and the individuals with disabilities to locate educational programs or practitioners who can provide such programs either for groups or individuals. The issue is not specifically related to sterilisation or other sexual and reproductive health issues, but to the general issue of access to and provision of health services for people with disabilities, in accord with UN Conventions.

***(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***

The response to the above heading is mirrored here. Health professionals cannot know about and access services and programs for people with disabilities if they cannot recognise and adequately communicate with and treat people with disabilities. It is not only health professionals who need greater access to education and knowledge about resources; legal training especially for lawyers on Guardianship Tribunals or the equivalent, and those involved in separate representation, for example, also needs to be more thorough and extensive.

Research in the USA has shown that attitudes towards the expression of sexuality amongst people with an intellectual disability have become more positive over the past 30 years with an overwhelming majority of parents of people with intellectual disability now reacting positively to consensual sex between adults with an intellectual disability (Cuskelly and Bryde 2004). In some nations, support staff and community members also now have more positive attitudes towards the sexuality of people with intellectual disability, although there continues to be caution about the parenting capacity of this group (Gilmore and Chambers 2010). Whilst attitudes change, however, provision of services does not.

**(h) any other related matters**

Despite a yawning gap in the knowledge base of health professionals, individual carers/family members, and carer organisations about sexual and reproductive health issues relating to people with disabilities, and the difficulties in accessing services and programs, in

my experience once the issue of sterilisation is raised, that issue is comprehensively, ethically and compassionately addressed. All parties usually make a concerted and genuine effort to take the best interests of the person into account, and locate independent assessment and advice to assist the decision-making body.

It has been suggested that in order to ensure that no sterilisation procedures are conducted without appropriate consent, or which are not in the best interests of the individual with disability, national registers of involuntary sterilisation procedures should be established.

In general, countries which maintain a strong mainstreaming policy regarding people with intellectual disabilities regard registers as in conflict with such a policy, unethical and possibly a source of discrimination. Furthermore, maintaining a register is expensive, and the reliability of diagnoses and compliance with inclusion criteria cannot be guaranteed (Westerinen, Kaski et al. 2007). Some countries have registers of people who receive services or benefits, but these may not comprise all persons with disabilities (Westerinen, Kaski et al. 2007) and are likely to be de-identified and therefore provide only statistical or planning information. Registers may impinge upon the principles of confidentiality and privacy of medical information. Lastly, people with intellectual disabilities may not want to be on a national register and they and their families may, with some justification, feel that they have a right to choose to disclose or not disclose their condition of intellectual disability and their medical and other reasons for electing to undergo a sterilisation procedure.

It is difficult to envisage how a register of involuntary sterilisation procedures for people with intellectual disabilities would work (even if the ethical and practical considerations of maintaining such a register could be overcome). Even the term “involuntary sterilisation” may be difficult to define. It is possible that a register of all sterilisation procedures in which third party consent was given could be kept, although there remains the possibility that the individual may give consent under duress or as a result of mis-information and therefore a third party consent would not be recorded. One possibility is that all persons undergoing sterilisation procedures could be assessed for capacity to give informed and valid consent and those who lack capacity could be included on the register; this may not sit well with the general population. Although in theory any lack of capacity ought to be noted by the treating medical practitioners and consequently third party consent procedures brought into play, in practice it could be seen as unjustified and intrusive interference in the rights of the individuals to control their own fertility. Lastly, the existence of a register may give rise to alternative justifications for the sterilisation, for example, falsely indicating that the procedure was undertaken for therapeutic reasons.

Another possibility is that there could be a register of all Court or tribunal decisions about non-therapeutic sterilisation; this option may work in jurisdictions where prescribed procedures for third party consent are strictly adhered to. However, again the information would need to be de-identified. Another result may be that families, carers and health professionals may invent or over-emphasise a medical reason for the procedure.

Rather than establish a national register of involuntary sterilisation, it is more important and more likely to achieve the aims of preventing unjustifiable non-therapeutic sterilisation of people with intellectual disabilities, if legislation and policies are monitored for compliance with UN Conventions.

## APPENDIX A

### Case histories of people with intellectual and other disabilities

Proceedings	Details of client	Issues
<p>Application by the treating gynaecologist, to the NSW Guardianship Tribunal for consent to a special medical procedure, namely consent to perform an endometrial ablation on Client A.</p>	<p><b>Client A</b> - Female, aged 22, born with Down Syndrome. <b>Support needs:</b> Resides at home with foster mother, attends a supported program, ratio of three clients to one staff member between the hours of 9 a.m. and 3 p.m; transport provided to and from the day program. Requires considerable supervision at the centre and in the community. Has difficulty with toileting and menstruation, and severe anxiety. <b>Medical:</b> Client A suffers from heavy and frequent menstrual bleeding which is not able to be controlled by interventions trialled by her gynaecologist. Menstrual bleeding can continue for 16 days; she cannot manage menstruation or toileting independently. She had two Implanon implants, two years apart. Despite this she experienced breakthrough bleeding which sometimes lasted for weeks. According to the foster mother, Client A's behaviour, abilities and activities of daily life have regressed severely, the regression appearing to have coincided with the second Implanon implant. <b>Disability:</b> Severe intellectual disability, for both cognitive functioning and adaptive behaviour. Functional age equivalent of &lt;4 years for cognitive reasoning, and 1 year 11 months through to 3 years 11 months for adaptive behaviour.</p>	<p><b>Ability to give consent:</b> Expert opinion was that she is unable to comprehend the nature and effect of the procedure and, therefore, would be unable to give an informed consent. She is unable to comprehend pregnancy or childbirth and would be unable to express or understand a willingness to have a child. <b>Quality of life:</b> The problems of soiling, the amount of 1:1 staff time required to attend to her toileting and menstrual needs, missing out on activities and community involvement, and the difficulties in managing the menstrual periods, especially when the client is in the community, could be alleviated by the endometrial ablation. The fairly minor procedure would have the effect of enhancing her quality of life and removing one difficult area of personal hygiene and management which could provide a quite significant enhancement to her overall quality of life. Irrespective of whether or not the client's behavioural difficulties are related to the menstrual periods, the effects of endometrial ablation would be to provide some small but significant increase in her quality of life by doing away with a difficult personal hygiene issue.</p>

<p>Mother made an application to the Family Court of Australia seeking authorisation for a hysterectomy to be carried out on her daughter.</p>	<p><b>Client B:</b> Female, aged 12 with global developmental delay and numerous medical problems.  <b>Support needs:</b> Resides at home with mother; maternal grandparents assist with care; she attends a special school.  <b>Medical:</b> GP reports global developmental delay; intellectual disability and motor delays; unspecified craniofacial dysmorphism syndrome; epilepsy; congenital macrothrombocytopaenia (resulting in defects in blood clotting); hypercalciuria; severe dysfunctional uterine bleeding and abnormal, lengthy heavy periods; severe iron deficiency anaemia as a result of heavy blood loss during heavy menstrual periods; asthma; gastro-oesophageal reflux disease; obsessive compulsive disorder; chronic constipation; obesity; sleep apnoea. Multiple medications and treating specialists involved in her medical care. Her response to hormone treatment and the contraceptive pill is problematic.  <b>Disability:</b> Cognitive reasoning could not be assessed during consultation owing to behavioural problems; previous assessment showed moderate intellectual disability. Mild-moderate adaptive behaviour deficits; functional age equivalents 1 year 4 months through to 4 years 10 months.</p>	<p><b>Ability to give consent:</b> Client B does not understand the nature and effect of the proposed procedure and will not understand in the future. She does not understand the concept of becoming pregnant or having a child.  <b>Quality of life:</b> There may be a reduction in her seizures. The condition of anaemia resulting from severe and lengthy periods will probably reduce because she was not anaemic before the onset of menstrual periods. Her platelet count will probably stabilise rather than fall, because she will not be losing blood. Therefore her fatigue will lessen. She will be able to enjoy activities that she previously enjoyed prior to menarche, such as going to the beach, swimming, playing tennis and participating in other athletic, social, and peer group activities at school, and also when she is on respite care. The proposed procedure would result in a reduction in the amount of medication that she takes because she would no longer need to take the medication which is necessary to try to control the excessive menstrual bleeding</p>
<p>Provision of an expert opinion to the Family Court, in respect to an Application by the parents for an order authorising a hysterectomy for their daughter.</p>	<p><b>Client C:</b> Female, aged 13, born with tuberous sclerosis, and epilepsy from age 6 weeks.  <b>Support needs:</b> Living at home with parents and two younger brothers, attending a special school. She cannot change a sanitary pad, and is not aware that</p>	<p><b>Ability to give consent:</b> Client C is unable to understand the nature and effect of the proposed procedure or to give informed consent to the hysterectomy. She will not be able to give such consent</p>

	<p>she needs to wear a pad; she will not be capable of managing her menstruation in the future. She was toilet trained at the age of 9, but cannot toilet independently.</p> <p><b>Medical:</b> History of petit mal and unusual complex seizures for which she is prescribed medication. Seizures changed, and became more tonic, generalised seizures since onset of menstruation, occurring almost daily, causing falls and injuries. She has been tried on a number of contraceptive pills of varying strengths, and has generally suffered some form of breakthrough bleeding.</p> <p><b>Disability:</b> Moderate-severe intellectual disability and adaptive behaviour levels, functioning between 1 year 6 month and 2 years 11 months.</p>	<p>in the future. She has no understanding of sexual relationships or of pregnancy, and is unlikely to develop these concepts.</p> <p><b>Quality of life:</b> A training program to address her needs in relation to management of menstruation did not make any major gains, and at best enabled her to partly place a pad in her own underwear when prompted to do so. She did not recognise when she had to insert the pad, unless prompted, and nor would she recognise when she had to change the pad. With a functional age of around about two years, her understanding of sexuality would not be improved by any educational program, and she would never be able to understand the complexity of sexual intercourse, sexual relations, or consent to sexual activity. Her quality of life would be marginally improved by authorisation of the procedure of hysterectomy. She reacts negatively towards her periods. She suffers from some discomfort. The school copes well with the management of her menstrual hygiene, but this may not be the case once she leaves school and attends post-school options. In the short term and the long term life would be simpler for the client, and she would have more opportunities for social interactions and participation if programs if she were not having menstrual periods.</p>
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