

Submission

To

The Standing Committee of Attorneys General

In response to

Issues Paper, September 2006,

Regarding

The Sterilization of Intellectually Disabled Minors.

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Sterilization of Intellectually Disabled Minors
(Standing Committee of Attorneys General)

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1. Introduction:

In recent decades great advances have been made in changing attitudes in our society for the better in regards to how we care for intellectually disabled persons. In the last twenty years we have come to understand that people with Down Syndrome, for example, have delayed learning capabilities that can be nurtured with structured methods; whereas, in earlier times institutionalization was the predominant outcome with little or no expectation for development.

In this context, we seriously question the development of a national approach to the sterilization of minors with an intellectual disability. We believe that sterilization for any reason other than therapeutic necessity should not be allowed and that appropriate support and training for parents/carers and their children should become the normative response to what we recognize are difficult circumstances.

The Catechism of the Catholic Church says:

“Except where performed for strictly therapeutic medical reasons, directly intended amputations, mutilations and sterilizations performed on innocent persons are against the moral law.”¹

This submission wishes to begin by making perfectly clear the Catholic Church’s opposition to sterilization for any reason other than for *strictly therapeutic medical reasons*.

To sterilize a child with an intellectual disability without therapeutic cause would be to deny the child its rights to enjoy bodily integrity and also to place an artificial limit on the child’s potential for development. We understand the term ‘fullest possible’ as used in the *UN Convention on the Rights of the Child* to mean essentially ‘without artificial limit’.

Article 23

- 1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.*
- 2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.*
- 3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities **in a manner conducive to the child's achieving the fullest possible social integration and individual development**, including his or her cultural and spiritual development. [Emphasis added]²*

¹ CCC # 2297 On Respect for Bodily Integrity.

² UN Convention on the Rights of the Child see: <http://www.unhcr.ch/html/menu3/b/k2crc.htm>

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In 2006, the eighth session of the UN Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities published its *Draft Convention on the Rights of Persons with Disabilities*. This document made no distinction between types of disabilities.

Article 23 – Respect for Home and the Family

1. 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:

(a) 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;

(b) The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognised, and the means necessary to enable them to exercise these rights;

(c) Persons with disabilities, including children, shall retain their fertility on an equal basis with others. [Emphasis added]³

In an earlier session, an intervention by three Australian NGOs recommended that sterilization other than for therapeutic purposes should be comprehensively banned:

“We believe this convention must contain an explicit prohibition on the sterilization of children and adults with disability for non-therapeutic purposes (by “non-therapeutic” we mean sterilization other than that necessary for therapeutic purposes to save life or avoid serious illness). Non-therapeutic sterilization, whether ‘forced’ or not, is a violation of fundamental human rights. It is not sufficient to provide protection against forced sterilization, as sterilization of children most often occurs at the request of a parent, as guardian of the child, rather than as a result of State action. In this respect it is ‘voluntary’ rather than coerced. The prohibition on non-therapeutic sterilization must therefore also encompass voluntary conduct by parents and others seeking sterilization of their children.”⁴

Article 23(1)(c) on the retention of fertility ‘on an equal basis with others’ is essentially a short-hand version of the above holding the same meaning and intention. The inclusion of what we might call the ‘equal basis’ test is similar to the ‘but for’ test argued later in this submission. (See section 5)

We are concerned that the proposal for a national approach to the authorization of procedures differs little from current practice in one crucial matter at least: that the focus appears to be on the outcome rather than the rights and needs of the individual person. We will develop this argument later on, posing the question: “Who does this serve?”

We recognise that the care and support of children with an intellectual disability can be incredibly complex and demanding. Parents and carers are right to be concerned about managing fertility issues for young women in their care. However, we believe that an intervention by way of non-therapeutic sterilization should never be seen as an

³ Draft Convention on the Rights of Persons with Disabilities see: <http://www.un.org/esa/socdev/enable/rights/ahc8adart.htm>

⁴ NGO Intervention Third Session see: <http://www.un.org/esa/socdev/enable/rights/ahc3ngo14.htm>

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appropriate answer. If there is an identifiable and pressing need for parents and carers alike then surely the answer lies in carefully structured education, behaviour management and supervision. Sterilization, in this context is either a matter of active discrimination against the rights of the intellectually disabled, a counsel of defeat, or both.

2. On Consent:

In the 1992 Marion's Case the majority of Justices (4/3) determined that applications for the non-therapeutic sterilizations on minors should be heard by a Court. This appears to be recognition as to the gravity of the decision itself and acknowledgement that parents cannot always be entirely objective in such matters.

In his dissenting remarks, Justice Brennan made some observations about the whole idea of consent:

"It is misleading to speak of an authorization given by a third party to administer medical treatment to an intellectually disabled child as a substituted consent. "Substituted consent" is semantic legerdemain (133) See Matter of Guardianship of Eberhardy (1981) Wis 307 NW 2d 881, at p 893, where the Court, speaking of authorization of sterilization of a mentally incompetent child said: "It clearly is not a personal choice, and no amount of legal legerdemain can make it so." Such an authorization is the very antithesis of consent, for it authorizes the administration of medical treatment to the child irrespective of consent.

"But it must be remembered that, in the absence of legal rules or a hierarchy of values, the best interests approach depends upon the value system of the decision-maker. Absent any rule or guideline, that approach simply creates an unexaminable discretion in the repository of the power. Who could then say that the repository of the power is right or wrong in deciding where the best interests of an intellectually disabled child might lie when there is no clear ethical consensus adopted by the community? An authorization to sterilize might be reviewable by a tribunal, but what guidance would the best interests approach give the tribunal?"

"For these reasons, I am unable to agree that either parents or guardians on the one hand or courts on the other possess any power under the general law to authorize the non-therapeutic sterilization of intellectually disabled children."⁵

The absence of the ability to understand the full extent of the procedure and, therefore, to give informed consent is not restricted simply to children and young adults with an intellectual disability. We argue that, because of the irreversible nature of the procedure, no minor, regardless of intellectual ability, should be sterilized unless for therapeutic reason.

No child is capable of fully informed consent in this regard. Even the application of the House of Lords *Gillick* test⁶ that suggests that developing the ability to consent is a gradual process cannot guarantee that a young person's developing capacity for reason is

⁵ Brennan J in Marion's Case (Secretary, Dept of Health and Community Services v J.W.B. and S.M.B. (1992) 175 CLR 218 F.c. 92/010

⁶ *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112

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not compromised by external pressures. How much more so a young person with an intellectual disability?

‘Substituted consent’ implies that consent, by a third party or parties, is made where the individual concerned, but for their circumstances, would normally be able to make such consent. We say that this is never the case and find ourselves in agreement with Justice Brennan that, ‘*Such an authorization is the very antithesis of consent, for it authorizes the administration of medical treatment to the child irrespective of consent.*’

3. Reasons for sterilization:

The discussion paper and the draft bill do not specify the reasons why sterilization might be approved by the appropriate tribunal. Mention is made of why not:

*Eugenics; removal of the risk of pregnancy resulting from sexual abuse; because it is a convenient contraceptive or menstrual management issue.*⁷

[Note: We find it strange that these exclusions can, even so, be accepted by the tribunal as ‘contributing factors’ where the procedure is deemed ‘*also in the best interests of the child*’.⁸]

Therapeutic reasons, being properly excluded from the scope of the scheme, the only conclusion we can draw is that sterilization can take place for contraceptive reasons – to avoid pregnancy.

While the draft bill is clear that this cannot simply be a matter of convenience [10(4)(c)] and that, in the best interests of the child, ‘alternatives’ [10(1)(a)&(b)] should be explored (making sterilization an option of last resort) the scheme is, nonetheless, about contraception.

This is made all the more confusing because the implication, therefore, is that somehow the child is (or will be) capable of engaging in sexual activity by consent. While the ability to consent to sexual activity may well be a different level of cognitive decision making to a sterilization procedure, the whole basis of this scheme implies a lack of ability to consent which, as we have already said, must surely raise questions about consent in general.

While pregnancy may not be a desirable outcome for an intellectually disabled person and her carers to manage it is not a disease to be treated by such an invasive and irreversible procedure. As we have already highlighted; the right to bodily integrity and the ability to reproduce (fertility) are fundamental to personal identity regardless of intellectual ability.

⁷ Draft Bill Clause 10(4)(a)

⁸ Draft Bill Note on Clause 10(4)

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4. Who does this serve?

It is obvious that sterilization of minors with an intellectual disability primarily serves the needs of the parents/carers of the young person concerned. Women with Disabilities Australia (WWDA) canvassed this issue in their 1999 paper: *Sterilization of Women and Girls with Disabilities – A Literature Review*.

“Brady (1995/96/98) and with Grover (1997) has consistently claimed that if parents or care givers were offered alternatives to sterilisation, for example, respite, out of home and in-home care and special programs on hygiene and protective behaviours, the perceived need for non-therapeutic sterilisation would be eliminated. Brady claims that once parents are provided with alternatives the majority no longer seek consent to sterilise.”⁹

It is not legitimate to argue that, because pregnancy is an undesirable outcome, that sterilization is the answer. Clearly the correct answer is appropriate support, training and encouragement. Only then can we answer the question concerning who is being served in terms of the best interests of the child in both the present and future.

We hopefully would never seek such radical remedy for a minor without intellectual impairment - basic human dignity should demand the same in every case. The various existing schemes and the proposed national approach fail to serve the disabled young person; instead, objectifying them as a possible source of discomfort and difficulty for those charged with their care.

The proper role for the state is to offer appropriate support and guidance in due recognition of Article 23 of the UN Convention (cited above).

5. Tests: ‘but for’ or ‘best interest’?

We argue, save for recognised and defined therapeutic necessity, that it is never in the best interest of the child to be sterilized. A genuine ‘best interest’ test, in terms of the rights of the child, excluding therapeutic necessity, could never find in favour of sterilization.

In the United States, eugenic sterilization of minors with an intellectual disability was almost routine in some jurisdictions up until the 1970s. In September 2006, the *Chicago Tribune* ran a chilling article around the plight of women who were sterilized (some without knowledge) as children who later married and were unable to conceive.¹⁰

This calls into question the principle of the ‘best interest’ test on the basis that, for some women at least, early childhood intellectual disabilities can and often are overcome in later life.

It is also likely that the sterilization procedure will create later hormonal complications, particularly if conducted prior to the onset of puberty.

⁹ See: www.wwda.org.au/steril.htm

¹⁰ See www.chicagotribune.com article Sept 6, 2006 ‘Sterile victims stand up...’

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In their 1997 report to the Human Rights and Equal Opportunities Commission on *The Sterilisation of Girls and Young Women in Australia*¹¹, Susan Brady and Dr. Sonia Grover made a case for the use of a 'But for' test in respect to any determination vis-à-vis a therapeutic necessity for sterilization. They noted that in the case of PVP No. 2 (1994 19 FamLR 1), Justice Nicolson had rejected the 'But for' argument as a test of the best interest of the child. However, we believe that there is a strong case for arguing that we should always ask: 'Would sterilization be recommended but for the child's intellectual disability?' Not to ask such a question is to deny the child's basic rights and, further, to negate her right to be treated objectively in advocacy and as a human person on an equal basis with her peers and humanity in general.

6. Sterilization – under the radar

In their report to HREOC, Brady and Grover observe that in the period from 1992 (Following the High Court decision in Marion's Case) to 1997 more than 1000 sterilizations took place without proper reference to the Family Court or State tribunals. While these figures have been questioned, no-one seems to be denying that a number of sterilization procedures have been undertaken without due process.

Brady and Grover suggest that there may well be an element of ignorance in respect to the law on the part of some in the medical profession. It is also possible that, for some procedures, the lack of clarity about parental ability to give consent and the lack of clear guidelines as to what is genuinely therapeutic may be contributing factors.

There is clearly a great need for clarity on what is considered as therapeutic. This information needs to be widely disseminated through the medical community. It needs to be made perfectly clear that, outside these clear guidelines, sterilization cannot go ahead without the formal consent of the appropriate authority. It should be made explicit that parents cannot give consent at all outside of therapeutic necessity so defined. The medical profession should also be reminded that any operation on a minor without proper consent constitutes an offence.

7. Summary and recommendation:

While we recognize that the intention of the issues paper is essentially to develop *a nationally consistent approach to the authorization procedures required for the lawful sterilization of minors with a decision-making disability*, we do not accept that the sterilization of any minor for non-therapeutic reasons can ever be an acceptable outcome.

Any application of a true 'best interest' or 'but for' test, in keeping with UN conventions and guidelines and cognizant of human dignity, can never be found in support of sterilization of any minor.

¹¹ See www.hreoc.gov.au/disability_rights/sterilisation/index.html

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We recommend that the Standing Committee of Attorneys General reject the impetus of the Issues Paper and draft legislation. We strongly recommend that the practice of sterilization of minors for any reason other than those strictly defined as therapeutic should cease and be replaced by an educational support scheme that truly values intellectually disabled persons as members of our community.

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