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Standing Committee on Community Affairs
Attention: Mr Ian Holland
PO Box 6100
Parliament House
CANBERRA ACT 2600

Dear Standing Committee on Community Affairs

Thank you for providing the Australian Medical Association (AMA) with the opportunity to make a submission to the *Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia.* In recognising that Australia has ratified the *Convention on the Rights of Persons with Disabilities*, it is particularly important to address the issue of involuntary or coerced sterilisation to ensure people with disabilities are being treated with the same respect for autonomy, dignity, and privacy as everyone else.

AMA position
The AMA believes that all people should be aware of, and have access to, family planning information and services, including contraception and sterilisation.

Consent to sterilisation should be free from material or social incentives which might distort freedom of choice and should not be a condition of other medical care (including safe abortion), social, insurance, institutional or other benefits.[1]

Support for people with disabilities
There should be appropriate education and support for people with disabilities, including cognitive disabilities, their carers, and health care professionals in relation to managing sexual and reproductive health. There should be appropriate education and support for parents with disabilities, including cognitive disabilities, who require assistance in caring for their children.

Support for carers[2]
Caring for family members or friends with disabilities can be both rewarding and challenging. Carers are known, however, to have poorer health and well-being than non-carers and may face financial, emotional, and other difficulties in relation to their caring responsibilities. Carers play an important role in the Australian community and deserve appropriate government and community support to assist them.

[1] World Medical Association. *WMA Statement on Forced and Coerced Sterilisation.* Adopted by the 63rd WMA General Assembly, Bangkok, Thailand, October 2012.
[2] Carers Australia. http://www.carersaustralia.com.au.

The doctor's role as patient advocate

The health and well-being of the individual patient is always the doctor's priority, regardless of the interests of third parties including the patient's carers, family members, or the wider community.[3] Patients with disabilities, and patients who lack decision-making capacity, deserve the same respect and dignity as all patients.

An important ethos of the medical profession is respect for patient autonomy, where patients have the right to make their own informed decisions regarding their health care, regardless of disability. An important role of the doctor is to obtain the patient's consent to treatment (an exception may be made in an emergency situation). Where a patient is unable to consent due to a lack of decision-making capacity, the consent of the patient's substitute decision-maker must be obtained.

For consent to be valid, it must be informed, voluntary, and the patient (or substitute decision-maker) should understand the benefits and risks involved in any recommended treatment.[4] By its nature, a valid consent cannot be involuntary or coerced. A doctor may face disciplinary action if he or she conducts an examination, investigation, or treatment of a patient in the absence of a valid consent.[4]

Sterilisation should only be performed for a competent patient after an informed choice is made and consent obtained. Where a patient is considered to permanently lack capacity to make a serious health care decision such as sterilisation, a substitute decision maker is required to provide consent; however, the patient should be encouraged to participate in the decision-making process as much as possible.

Surrogate consent to sterilisation must be in the patient's best interests, not the interests of others. The determination of best interests requires clinical advice from the patient's doctor(s) regarding current (and possibly future) health conditions, decision-making capacity, and health needs. The doctor can discuss the risks and benefits of contraception, including sterilisation, with the surrogate and the patient (where appropriate) and advise on the treatment that best serves the patient's health needs.

For a patient who lacks decision-making capacity, it is important to determine whether the situation is temporary (for example, in a patient with a minor brain injury), fluctuating over time (for example, in a patient with dementia), or permanent. Unless the situation is an emergency, people with temporary or fluctuating capacity should be allowed to recover their decision-making capacity so their consent may be sought for treatment.

Options to sterilisation

Sterilisation should be considered an irreversible form of contraception; therefore, temporary and reversible methods such as oral or injected contraceptives should generally be considered first.

[3] World Medical Association. *Declaration of Seoul on Professional Autonomy and Clinical Independence.* Adopted by the World Medical Association General Assembly, Seoul, Korea, October 2008.
[4] Medical Board of Australia. *Good Medical Practice: A Code of Conduct for Doctors in Australia.*

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists advises that:

In addressing 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 an intellectual disability, are the most appropriate. Reversible methods such as long acting reversible contraceptive implants (eg., Implanon or Mirena) should be considered in preference to irreversible surgical options.[5]

Whilst sterilisation for a patient lacking decision-making capacity would be rare, there may be extreme cases where sterilisation is the best therapeutic option and last resort (for example, where other forms of contraception have failed).

We look forward to the outcomes of the Inquiry.

Sincerely

Dr Steve Hambleton
President

12 March 2013

[5] The Royal Australian and New Zealand College of Obstetricians and Gynaecologists. *C-Gyn 10. Sterilisation procedures for women with an intellectual disability.* March 2010.