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Senator Siewert
Chair
Senate Standing Committees on Community Affairs, References Committee
PO Box 6100
Parliament House
Canberra
ACT 2600

By email: community.affairs.sen@aph.gov.au

Dear Chair and Members

Senate Inquiry - *The involuntary or coerced sterilisation of people with disabilities in Australia*

Thank you for the opportunity to make a submission with regard to the above reference. This submission is written on behalf of the Australian Guardianship and Administration Council (AGAC).

AGAC is comprised of the Public Guardians, Adult Guardians and Public Advocates, the Boards and Tribunals who deliberate upon applications under guardianship and administration legislation and the State Trustees or Public Trustees.

The subject of this inquiry is of particular interest to the members of AGAC who hear applications for consent to sterilisations within the Guardianship Tribunals, Boards or Lists in each jurisdiction and the Public Guardians, Adult Guardians or Public Advocates in each jurisdiction.

Attached is a protocol that members of AGAC adopted on 30 March 2009 relating to applications for consent to sterilisations. This can also be accessed at: http://www.agac.org.au/agac-publications. AGAC members continue to refer to that protocol in relevant applications. You will note that the protocol sets out the relevant State and Territory legislative provisions (at the time of adoption) and that the Aims and Objectives of the protocol are as follows:

> *"3. Aims and objectives*

3.1 Procedurally, the Protocol aims to:

(a) Set out the matters to be considered by tribunals hearing cases for the proposed sterilisation of persons.

(b) Achieve as much consistency as possible between the jurisdictions.

(c) Ensure that the matter proceeds in a timely manner and that all necessary evidence is placed before the tribunal.

3.2 For the person and their carers, the aim of the Protocol is to:

(a) Promote, enhance and protect the best interests of the person.

(b) Promote positive outcomes for the person.

(c) Give the people involved or concerned in the decision an opportunity and forum to raise and discuss all relevant issues.

(d) Ensure that alternative and less invasive procedures have been tried or considered.

(e) Ensure that sterilisation is a last resort, after other options have failed to produce outcomes satisfactory to the person.

(f) Ensure clarification of and delineation between what is in the best interests of the person and what is in the interests of the person's care giver/s."

AGAC provides the following submissions against 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;

All Guardianship Tribunals or lists in Australia report a very low incidence of applications for consent to sterilisations. This might suggest that where contraception or menstrual management is required for persons with decision-making disabilities, forms of treatment other than irreversible sterilisation are generally adopted such as oral contraceptive pill, condoms or diaphragms, inter-uterine devices, implants or depot injections.

Where a person lacks capacity to understand medical treatment, consent for reversible contraceptive treatments can be given by guardians, persons responsible or a statutory health attorney. The only circumstances where a statutory guardian would be involved in decision making about reversible contraceptive treatments would be in circumstances where a decision is required in the best interests of the person with a disability or where the decision is attended by conflict. A guardian, person responsible or statutory health attorney must take into account the best interests of the person, the person's wishes and the alternative that will best promote the person's freedom of decision and action.

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

The only data that would be available to AGAC members would be the number of applications to Guardianship Tribunals or lists in Australia that are received for consent to irreversible sterilisations. As noted above, these numbers are generally very low, usually only one to two applications in each jurisdiction each year.

This figure would not take into account procedures where:

- a person with a disability is deemed to have capacity to consent to the sterilisation,
- the procedure is undertaken for life saving purposes, which is lawful in some jurisdictions, or
- consent is not sought and/or the procedure is undertaken unlawfully.

(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;

An involuntary or coerced sterilisation of a person with a disability, or any person, is an assault against the person which could result in criminal prosecution and proceedings for civil remedies.

A person, including a person with a disability, is presumed to be capable of giving or refusing consent to medical treatment, including a sterilisation.

Where there is evidence that a person with a disability, by reason of a disability, is unable to give informed consent or refusal to medical treatment, guardianship legislation in each State and Territory establishes the parameters for a tribunal or court to give consent to or refuse such treatments. These treatments are referred to as 'special treatments' and 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."

The Australian Guardianship and Administration Council (AGAC) *Protocol for Special Medical Procedures (Sterilisation) 6 May 2009*[1] (the AGAC protocol) is applied in applications for special treatments.

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

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

See 'Part 4 – Decision Making Principles' of the AGAC Protocol.

By way of example, please see the decision of the Tasmanian Guardianship and Administration Board in *UHM (Medical Consent)* [2011] TASGAB 12[2]. In the decision the Board had been informed by the applicant that UHM wanted to have the sterilisation

[1] http://www.agac.org.au/images/stories/agac_sterilisation_protocal_30_mar_09.pdf

[2] Available at: http://www.austlii.edu.au/au/cases/tas/TASGAB/

procedure, but the Board required the Public Guardian to independently investigate UHM's wishes and alert her to her right to representation in the case.

In *MG (Medical Consent)* [2004] TASGAB 5, the wishes of MG were unascertainable and the Board refused consent to treat.

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

See Part 5 of the AGAC protocol.

(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

See Part 5.21 of the AGAC Protocol

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

Since Australia ratified the *United Nations Convention on the Rights of Persons with Disabilities* there has been more focus upon 'supported decision making' and less focus on the paternalism of imposing 'best interests' judgments. However, the 'best interests' test remains a feature of guardianship legislation.

In *MG (Medical Consent)* [2004] TASGAB 5, the Board assessed that it was not in MG's best interests to consent to the procedure as less restrictive techniques had not been attempted and MG was still a very young person.

In *UHM (Medical Consent)* [2011] TASGAB 12, UHM had a serious gynaecological condition which needed to be addressed by surgery. In that decision the Board gave detailed consideration to the statutory elements that establish a person's best interests. In essence, the Board's consent in that case was of the nature of a 'supported decision', in that the proposed patient wanted the procedure and the Board's decision supported that outcome after careful analysis of her capacity to make that decision and her best interests.

Other unreported cases include:

- A situation where, after giving birth to her fifth child, a woman with an intellectual disability had a prolapsed uterus and another pregnancy would have been life-threatening for her. She wanted to have the procedure, but her reasons for wanting the procedure were that her children had all been removed by Child Protection, rather than for medical reasons. The Board agreed that she needed the procedure for medical reasons and lacked capacity to understand the consequences of not having the procedure.

- A young person, who was born male, wanted to undergo gender reassignment surgery which would have had the effect of rendering the person infertile. The person had a mild intellectual disability and had clearly been living as a female for a significant period. While she understood and deeply desired the outcomes of the surgery, there were complex aspects of the procedure that she was unable to give informed consent

to, because of her intellectual disability. Surgeons performing the procedure would not accept her consent and required the consent of the Board.

(e) the impacts of sterilisation of people with disabilities;

AGAC considers that persons with disabilities and disability advocacy agencies would be better placed to comment on this term of reference.

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

Article 23 of the *United Nations Convention on the Rights of Persons with Disabilities* which has been ratified by Australia along with the Optional Protocol states:

> "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 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."

AGAC believes that the Protocol and the application of current guardianship legislation is consistent with these rights.

(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

AGAC considers that persons with disabilities, disability advocacy agencies and care providers would be better placed to comment on this term of reference.

(h) any other related matters.
No suggested response