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20 February 2013

Mr Ian Holland
Committee Secretary
Standing Committee on Community Affairs
The Senate
PO Box 6100
Parliament House
CANBERRA ACT 2600

Dear Mr Holland

Re: Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia – Submission from the Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Please find enclosed the submission of the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) to the Senate Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia.

Any questions regarding the submission should be directed to:

Professor Michael Permezel, President
Royal Australian and New Zealand College of Obstetricians and Gynaecologists
College House
254-260 Albert Street, East Melbourne, Victoria 3002

The College would be pleased to clarify any part of our submission if requested.

Yours sincerely

Professor Michael Permezel
President

encl

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Senate Standing Committee on Community Affairs

Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia

Response from the Royal Australian and New Zealand College of Obstetricians and Gynaecologists

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) welcomes the opportunity to provide this submission to the Senate Standing Committee on Community Affairs.

General Comments

The RANZCOG is the lead standards body in women's health in Australia and New Zealand, with responsibility for postgraduate education, accreditation, recertification and the continuing professional development of practitioners in women's health, including both specialist obstetricians and gynaecologists and GP obstetricians.

Central Role of the Obstetrician and Gynaecologist

An experienced Gynaecologist is of prime importance in providing the best reproductive health management available as well as conveying compassion and empathy for the disabled girl or woman and her carers.

Alternatives to Sterilisation

The availability of safe and effective long-acting reversible contraceptives (LARCs), contraceptives that have the added benefit of reducing or eliminating menstrual flow, has greatly reduced the need for surgical sterilisation or hysterectomy of younger women in the last decade. However, no method of menstrual regulation or sterilisation is perfect, and a small number of disabled girls or women may still have their best interests served by hysterectomy or sterilisation. Information on some LARCs is outlined below.

Mirena

The Levonorgestrel-releasing intrauterine system (LR-IUS, Mirena) provides effective contraception for up to five (5) years, and is in widespread use in the community. Data attests to the safety of Mirena in nulliparous women (i.e. women who have never given birth). In 2012, the physically smaller three-year version – "Skyla" (13.5mg levonorgestrel) was launched in the United States. Mirena is 3.2x3.2 cm and suitable for a uterine cavity 6 to 10 cm, while Skyla is 3.0x2.8 cm and has been specifically designed for nulliparous women.

It is, however, important that the Committee recognises that Mirena is not a panacea for all women. Some will be troubled by continuous light menstrual bleeding. This is usually only of a few months duration, but can, in rare cases, extend indefinitely. Mirena is also contraindicated by pelvic infection, and there are a group of sexually-active disabled women at particularly high risk of sexually transmitted diseases. Mirena is not appropriate for these women.

Implanon

Implanon (etonogestrol) is a subcutaneous implant with an effective duration of three (3) years. It is an effective contraceptive but may cause menstrual irregularity, and has a variable impact on menstrual flow.

Depo-Provera

Depo-Provera (medroxyprogesterone 150 mg in a sesame oil base) intramuscular injection every 12 weeks has been in use for decades as a long-acting reversible contraceptive. After two injections, most women will cease menstruating. Depo-Provera has a comparatively higher rate of reported side effects, such as weight gain and in some cases an increased incidence of depression. It does not require a surgical procedure for insertion, but its use is limited by the risk of osteoporosis after five years.

It should also be noted that LARCs (e.g. Depo-Provera, Implanon) have the potential to interact with medications commonly in use for control of epilepsy and behavioural disturbance e.g. carbamazepine and phenytoin. Such interactions may decrease their contraceptive efficacy.

Legal Aspects

Consistency of Legislation across Jurisdictions within Australia

The College notes that the legal aspects may vary considerably across the different jurisdictions in Australia. This adds to confusion among health practitioners, affected families, and the public in general. Uniformity in the legislative framework would be of great benefit to all.

Consistency of Interpretations whilst allowing for Individual Circumstances

Families and their supporting medical practitioners would also be assisted by increased consistency in the interpretation of the relevant legislation in this area. That said, it is also important to recognise that the circumstances of every person and their family are different, with an allowance needing to be made for consideration of specific individual circumstances.

Equity of Access

All families affected must have equity of access through the legal system. The College notes with dismay that families applying through a court system may suffer financially when they may already be resource-poor and those limited resources are need to care for a child with a severe disability.

Simplicity of Process

An unnecessarily tortuous or complex legal framework may severely compromise, or even block, access for families to optimal treatment for an intellectually-disabled family member. It is imperative that the process of application be clear, transparent, and easy to negotiate for both the family and the medical practitioners providing evidence or support to that family.

Data Collection

The complexities of this area of practice appear to be severely affected by inaccuracies in data collection with inconsistencies across multiple sources. Where there is doubt as to the validity of data, its significance should be adjusted accordingly.

Example Case Vignettes

The following two actual case histories were submitted by a Fellow of the College active in this area of practice. The first case demonstrates disengagement with and failure of health providers to address the needs of intellectually disabled girls and women.

Case One

A young woman in her mid-20s with intellectual disability (IQ around 70) and unable to speak but not deaf was well known to a regional health service. She was from a small country town and had seven children all of whom had been serially handed to her ageing parents for care. Her parents begged the health facility for them to sterilise their daughter and an application was placed with the state guardianship board. This application was successful. Despite multiple attempts, the woman did not attend the booked procedure and two years later she had another baby. The process of applying for a court order with regard to sterilisation of the woman was started again; however, the guardianship board declined the request. The woman's parents were informed that nothing could be done. A few months later she fell pregnant again unfortunately to a new violent partner who eventually killed her during the pregnancy.

This case demonstrates inability of the health and disability services to engage the young woman in the simple matter of effective long term family planning. The guardianship board gave conflicting rulings thus distressing the elderly parents and providing uncertainty for the health service.

Case Two

Mary is just 16 and lives at home with her parents. She is the third of five children and was diagnosed with autism and moderate intellectual disability at the age of five. She is now home schooled as her behaviour deteriorates at special school and stress worsens her extreme anxiety; a trait common in autistic children. She is hyperactive and on Ritalin to modify her behaviour. Her mother attends to her showering and hygiene with great difficulty as Mary is combative about having showers etc. Mary began to menstruate at age 14. She has basic literacy but is regularly in touch with her friends on Facebook and enjoys horse riding and dancing lessons. She tells her mother she wants a boyfriend and wants to eventually marry and have babies. Unfortunately, Mary has other medical problems and recently had a nephrectomy for a dysplastic kidney causing hypertension. She has adrenal insufficiency and growth retardation and is dependent on daily cortisone. She has lapsed into a hypoglycaemic coma on several occasions and needs constant supervision. Her full adult height will be 152cm. Her mother dreads the week of her period as it causes much anxiety for Mary. Mary has some insight into her limitations and knows she is "different". Her mother will soon seek help and advice about Mary's menstrual and reproductive management.

Such a case poses many questions: how will the health service respond? What is in Mary's best interests? What is the legal situation if Mary refuses family planning when and if she becomes sexually active? The College therefore urges the Committee to consider measures that might be implemented in order to provide greater certainty to all those working and involved in this difficult area.

Summary Recommendations

No form of contraception or menstrual control is perfect, and it is not correct to state that LARCs such as Mirena, Implanon, or DepoProvera have completely removed the need for surgical measures in intellectually-disabled girls or women.

Legislation should be consistent across jurisdictions, and consistent in its interpretation. Flexibility to allow consideration of individual circumstances by determining boards / tribunals is vital.

RANZCOG agrees that the needs of the intellectually disabled girl/woman should be paramount, but those of lifelong dedicated carers should also be considered in an empathetic manner.