Australian Association of Developmental Disability Medicine Inc.

12 March 2013

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

RE: Senate Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia

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

We appreciate the opportunity to contribute to your inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities. The Australian Association of Developmental Disability Medicine (AADDM) is the national association of medical practitioners who work with children, adolescents and adults with intellectual and developmental disability. The goal of our association is to improve the physical and mental health of this population throughout Australia.

This submission outlines a number of principles and recommendations that serve to affirm the rights of people with disabilities in Australia and ensure appropriate equality of care:

1. Australia is a signatory to *The United Nations Convention on the Rights of Persons with Disabilities,* which emphasises that people with disabilities should be included fully within society. Article 25 recognises people with disabilities have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability. Specifically, Article 25 calls for the provision to persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.

2. People with disabilities have the same rights as all other people to exercise choices regarding sexual expression and relationships and have freedom over their body to make such choices. It is critical that the rights of people with disabilities are affirmed, defended, and respected. They have the right to individualised education and information to encourage informed sexual decision-making, including education about reproduction, marriage, safe sex practices, sexual orientation, abuse and sexually transmitted diseases.

We first note that although the inquiry understandably has a focus on females with intellectual disability (ID), males with ID can also be sterilised.

Females with ID have a wide range of abilities. Some are independent with some support and guidance, and can fully manage toileting, menstruation, contraception and possibly pregnancy. Others require full support for toileting, changing of continence aids and menstrual pads, cannot manage any form of menstrual management or contraception requiring cooperation.

Distinction needs to be made between menstrual management that is reversible, and the mostly irreversible tubal ligation and irreversible hysterectomy. The preferred options for menstrual management are those that are reversible, and include the Oral Contraceptive Pill (OCP) taken daily, a hormone injection every three months, a hormone implant under the skin of the left forearm, or a hormone implant in the uterus. More detailed description of each option is provided below.

Many females with ID have been prescribed the OCP for heavy and/or very painful periods. The OCP taken daily represents the least invasive medication and is easily reversed by discontinuing the tablets. This is most suitable for females with ID who will take the tablets regularly, either because they have 24 hour supervision at home or in accommodation services, or their ID is mild and they will be reliable taking the tablets. Many of those with more severe ID have weekly swimming lessons as part of their program, but unlike females in the general population, they may be unable to use internal protection, so they have to miss out on their swimming opportunity once a month. Even women without ID may take the active OCP continuously for almost four months, meaning a period only occurs every four months. So their female peers with ID do not have to miss their enjoyable swimming sessions. Parents/carers are advised by the medical practitioner to adjust the tablet regime so periods occur in the holidays. This is not only important to allow the female with ID to go swimming, it also overcomes her having to be kept home when she has her period because staff cannot help manage her period, or because of heavy blood loss or pain. This option is not available for females unable to swallow even the smallest of tablets, or who are unable to take anything by mouth and need to be tube fed.

Some females cope well with the hormone injection every three months, but many are terrified of needles, remembering past, unpleasant experiences.

The hormone implant under the skin lasts for three years, but for many females with ID it would need to be inserted and removed using a general anaesthetic. A number of females, particularly those with autism spectrum disorder or Asperger syndrome, dislike the feeling of a foreign body, and pick at the skin until they are able to pull the implant out. A female

with mild ID who had an implant commented that her physical education teacher took her arm to guide her during a session, and on feeling the implant, indicated he knew what the lump in her arm was. This is a potential breach of privacy, not usually experienced by girls who do not have ID or require physical assistance from teachers.

A hormone implant in the uterus lasts for five years, but also needs to be inserted and removed under general anaesthetic.

Females with ID during the reproductive ages often leave the family home and move into accommodation services, and may also move between accommodation services. Parents tend to maintain good records, and are able to remember information about their daughter, but health records tend not to be passed from one accommodation provider to the next. In particular, the information that the female has a hormone implant in the uterus may not be passed on to staff — consequently it may not be removed after five years, leading to a risk of complications. The eHealth record may help to overcome this issue, if the information is entered by the medical practitioner who inserted the implant.

Although there are a number of reversible options, they are not always options for females with ID. Difficulties arise if the female is unable to swallow or take anything by mouth, is terrified of needles, picks the skin to remove implants, or becomes upset at the sight of even a spot of blood (all the options discussed above have the risk of spotting, particularly towards the end of the estimated life of the product).

Many AADDM members report being consulted by females with ID who have been dissatisfied with their family GP. Some GPs and parents may not have ready access to comprehensive information about reversible menstrual management options. Many GPs do not feel comfortable relating to a female with ID who has difficulty communicating or is prone to aggressive outbursts. We have read that parent have taken their daughters with ID overseas for hysterectomies when reversible menstrual management has been considered inappropriate.

To address the complex challenges faced by women with disabilities and their families where reversible options are considered inappropriate we recommend the establishment of an Advisory Committee. Such state-based Advisory Committees would provide expert clinical advice to Guardianship Boards. The Advisory Committees should be composed of professionals with experience relating to females with ID, such as GPs, paediatricians, psychiatrists, psychologists and gynaecologists. The committees would consider whether medical management has adequately explored the least restrictive measures before an application for irreversible sterilisation for menstrual management is considered by the local Guardianship Board.

We urge the Senate to recommend to government that Australian and State and Territory Governments work together to redress the inequity in health care experienced by people with ID, including for females with ID in relation to menstrual management.

In particular, we seek recommendations from the Senate to:

1) Develop accessible resources for four groups:
   a) Women with disabilities
   b) Medical practitioners
   c) Parents
   d) Paid support workers and their managers.

2) Ensure resources contain detailed information about (i) preparing the female for menstruation; (ii) recognising when the female with ID is in pain (often presented as challenging behaviour); and (iii) options for menstrual management, including advantages and disadvantages; so all are better informed. Where possible, the process should build on what is currently available and increase access to this information.

3) Establish a national network of health services specialising in the healthcare of people with ID. These services would be a consultancy and training resource to the mainstream health system so as to enhance its capacity to meet the needs of people with ID. A KPMG report argues the case a network of health services specialising in the healthcare of people with ID to enhance the capacity of mainstream services; see http://www0.health.nsw.gov.au/pubs/2010/nsw_health_analysis.html

Thank you for the opportunity to present our concerns.

Yours sincerely

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