Senate Inquiry into Involuntary or Coerced Sterilisation

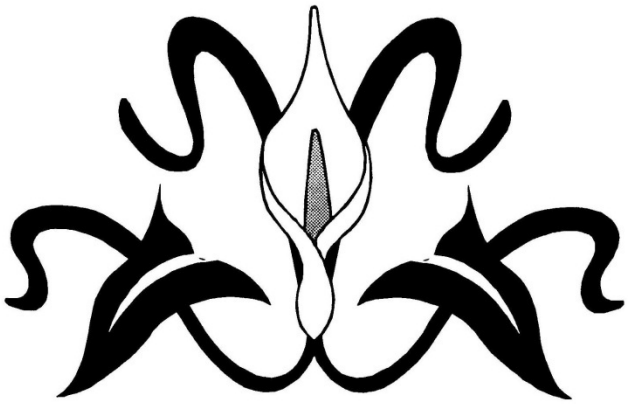
of

People with Disabilities in Australia

ANDROGEN INSENSITIVITY SYNDROME SUPPORT GROUP AUSTRALIA INC.

Submission

12 March 2013



AIS Support Group
Australia Inc.

About AISSGA

The Androgen Insensitivity Syndrome (AIS) Support Group Australia Inc. (A0041398U) is a peer support, information and advocacy group for people affected by AIS and/or related intersex conditions, and their families.

We support members (both in Australia and overseas) that have any grade of Androgen Insensitivity Syndrome, and support any issues relevant to living with AIS. These issues include infertility, disclosure, hormone therapy, gender identity, surgical intervention of children with intersex conditions, sexual intimacy, etc.

We also provide support to those with related intersex conditions like Partial and Complete / Gonadal Dysgenesis, MRKH (also known as Vaginal Agenesis), 5a-Reductase Deficiency, 3b-Hydroxysteroid Dehydrogenase Deficiency, 17-Ketosteroid Reductase Deficiency and 17b-Hydroxysteroid Deficiency. (The previous name for AIS was Testicular Feminisation Syndrome).

We acknowledge that people with intersex conditions (including AIS) range from female to male, both and anywhere in between.

The AISSG Australia believes in a holistic model of health as per the World Health Organisation definition of 'health':

> *"Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity".*

The AISSGA's main concern is the health, wellbeing and safety of both our members and the wider intersex community. We are making this submission to the senate committee in order to ensure adequate levels of legislative protection for our members and interest group.

Terms of Reference

This submission will refer to the following section of the terms of reference:

> *2. Current practices and policies relating to the involuntary or coerced sterilisation of intersex people, including:*
>
> *(a) sexual health and reproductive issues; and*
>
> *(b) the impacts on intersex people.*

Response

Intersex is a series of biological, genetic occurrences which are expressed in individuals as a physical divergence from classical views of male and female sex. Medical diagnosis is often (but not always) made in infancy or early childhood. It is our experience as a peer led support group that current medical protocol is to overly pathologise intersex bodies and seek to use surgical, hormonal and psycho-social methods to anatomically 'normalise' intersex bodies so that they more closely confirm with accepted standards of either male or female physiological stereotypes. Our anecdotal experiences are backed up by an ever-widening pool of research into contemporary medical practices and their effects on people with intersex conditions.

Sex normalization procedures are often carried out when the intersex individual is still an infant and can include both surgical and pharmacological intervention. These normalization procedures can and do have lasting adverse effects on the individuals' physical and psychological health. Although many intersex people are naturally infertile, this is not case universally. Many medical interventions to intersex bodies, particularly gonadectomy, can effectively be considered sterilization as they limit any future utilization of healthy reproductive tissue.

It is the AISSGA's view that any medical intervention to an intersex body needs to be 100% consented to by the individual and that they should be well informed, supported, connected with peer-based support services and be engaged in every stage of the decision making process. Medical protocol must ensure that all proposed interventions are presented in terms

of their documented long-term benefits and preserve as many options as possible for intersex people to remain self-determining with regards to their bodies and future life choices. Where a medical emergency exists and intervention is necessary to preserve life and the intersex person is not capable to make informed consent, the parents or legal guardians of this child need to be able to make consent based on full disclosure, and so should be well resourced, educated and connected to peer-based intersex support services.

Intersex individuals who have received pediatric treatment must be informed as soon as possible and receive thorough, ongoing care including access to appropriate hormone replacement therapy and psychological counseling. The AISSGA does not believe that preemptive removal of reproductive organs due to an inflated risk of cancer is necessarily appropriate in this age of modern screening and diagnostic technologies, and the benefits of retaining organs which produces natural, endogenous hormones rather than maintaining a lifelong course of synthetic HRT (hormone replacement therapy) once the gonads are removed are quantifiable.

Adverse affects of current medical normalization practices include:

- Psychological issues (depression, suicidal ideation, low self-view)
- Reduced sexual sensitivity and enjoyment
- Scarification
- Reliance on pharmaceutical hormones
- Oesteperosis
- Social stigmatision resulting from institutionalised secrecy around intersex issues
- Reduced reproductive freedom in respects to future reproductive technologies

RECOMMENDATIONS

1. The AISSGA calls for the human rights of intersex people to be identified and protected at every level of legislation and society.
2. Intersex people remain 100% consensual with regards to any surgical or pharmacological intervention of their body and that these procedures be indicated by documented long-term medical benefit.
3. The AISSGA calls for a moratorium on non-urgent medical intervention. This includes gonadectomies on intersex children and clitoral recession.

4. Reproductive freedoms for intersex people be maintained in terms of access to any future reproductive technologies.
5. The AISSGA supports the full disclosure of an intersex diagnosis to the parents and the affected individual at the earliest possible appropriate time.
6. That disclosure of intersex diagnosis be accompanied by a complete explanation of a full range of treatment options available, either for treatment or the likely outcome of non-intervention.
7. That parents and affected individuals should be advised of the existence of the support group and medical practitioners should recommend and explain the benefits of contact with the group.