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For intersex human rights, information, and peer support

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Submission on Australia and the Convention against Torture and Other Cruel Inhuman or Degrading Treatment or Punishment

1. About this report

This submission has been written by Organisation Intersex International Australia Limited.

It has been endorsed by the Androgen Insensitivity Syndrome Support Group Australia Inc., People with Disability Australia, Inc., and the National LGBTI Health Alliance.

Organisation Intersex International Australia Limited (“*OII Australia*”) is a national body by and for people with intersex variations. It promotes the human rights and bodily autonomy of intersex people in Australia, and provide information, education and peer support. OII Australia is a volunteer-led not-for-profit company, recognised by the Australian Taxation Office as a Public Benevolent Institution.

The Androgen Insensitivity Syndrome Support Group Australia (“*AISSGA*”) is a peer support, information and advocacy group for people affected by AIS and other intersex variations, and their families. It is a volunteer-led not-for-profit organisation.

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3. Intersex

Intersex is a term that relates to a broad range of congenital physical traits or variations that lie between stereotypical ideals of male and female. Intersex people are born with physical, hormonal or genetic features that are neither wholly female nor wholly male, or a combination of female and male.

Many forms of intersex exist; it is a spectrum or umbrella term, rather than a single category. At least 30 or 40 different variations are known to science¹; most are genetically determined. Clinicians currently use a stigmatising label, “*Disorders of Sex Development*”, to refer to intersex variations.

Intersex variations can include differences in the number of sex chromosomes, different tissue responses to sex hormones, or a different hormone balance. Examples of intersex variations include Androgen Insensitivity Syndrome (AIS), Congenital Adrenal Hyperplasia (CAH), and sex chromosome differences such as 47,XXY (often diagnosed as Klinefelter Syndrome) and 45,X0 (often diagnosed as Turner Syndrome).

Some common intersex variations are diagnosed prenatally. Intersex differences may be apparent at birth. Some intersex traits become apparent at puberty, or when trying to conceive, or through random chance.

People with intersex variations face a range of health and human rights issues. On the one hand these include deep-seated stigma, and medical interventions explicitly intended to make our bodies conform to social norms for a specific sex or gender. On the other hand, some people and institutions have inappropriate expectations that intersex people will openly challenge or transgress gender norms.

4. Our interest in the periodic report

This report details specific concerns relating to people with intersex variations and Australia’s compliance with the Convention Against Torture and Other Cruel Inhuman and or Degrading Treatment or Punishment (“CAT”). We recognise that the majority of issues raised in this report were not identified in the Committee’s List of Issues Prior to Reporting (“LOIPR”) but draw them to the Committee’s attention given they are significant areas where the Australian Government is failing to meet its obligations under the CAT.

In summary, this report details our concerns regarding the following:

- Involuntary or coerced treatment on intersex persons; and
- Disclosure and privacy issues related to body scans, searches and treatment of intersex prisoners.

5. Recommendations

The recommendations of the Senate inquiry report on *Involuntary or coerced sterilisation of intersex people in Australia* and the related report *Involuntary or coerced sterilisation of people with disabilities in Australia*⁴ need to be implemented. In particular:

¹ Olaf Hiort, 2013, *I-03 DSDnet: Formation of an open world-wide network on DSD* at clinician conference, “4th I-DSD Symposium”, June 2013: “*DSD comprise a heterogeneous group of differences of sex development with at least 40 different entities of which most are genetically determined. An exact diagnosis is lacking in 10 to 80% of the cases*”, http://www.gla.ac.uk/media/media_279274_en.pdf, accessed 1 July 2013.

- Australia must develop and enact national uniform legislation prohibiting the sterilisation of children, regardless of whether or not they are intersex or have a disability, in the absence of their prior, fully informed and free consent, except where there is a serious threat to life or health.
- Psychosocial rationales for surgical and hormonal interventions on persons with intersex variations, must no longer be permissible, or regarded as acceptable or therapeutic.
- Intersex women and girls must to be subject to the same policy arrangements on Female Genital Mutilation as non-intersex women and girls, with no applicable exemptions on cultural grounds, including grounds such as future marriage prospects.

Public services must meet the standards established by the *Sex Discrimination Act*¹⁸ and *Guidelines on Recognition of Sex and Gender*²⁰. Providers must ensure non-discriminatory treatment on the basis of intersex status and identified gender identities. The government should develop standards to ensure dignity and privacy in custodial, detention and security scanning.

6. Involuntary or coerced treatments on intersex persons

The UN Special Rapporteur on Torture and other cruel, inhuman or degrading treatment or punishment has identified that torture and other forms of ill-treatment are routinely carried out against intersex persons. Similarly, other UN agencies have expressed grave concern about such practices. Involuntary surgeries on intersex infants is an ongoing practice in Australia.

Paragraph 13 of the list of issues prior to Australia's fifth periodic report on the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (document CAT/C/AUS/Q/5²) asks Australia to effectively implement and enforce laws on violence against women, including the provision of statistical data and measures taken to ensure access to services. Document CAT/C/AUS/4-5, a January 2014 response to the list of issues, states that:

*Australia is working to help prevent violence against all women including Aboriginal and Torres Strait Islander women, rural women, women with disability, women identifying as lesbian, bisexual, transgender or intersex, and women from culturally and linguistically diverse backgrounds.*³

Between the publication of those two reports, the UN Special Rapporteur on Torture and a joint UN interagency statement on forced sterilisation have both raised specific concerns about how intersex children are subject to “sex normalizing” treatments with lifelong consequences, without their fully informed consent or that of their parents.

In Australia, a Senate Community Affairs References Committee report on the *Involuntary or coerced sterilisation of intersex people in Australia* published on 25 October 2013 identified that “sex normalizing” and sterilisation treatments occur in Australia⁴. The Committee found

² United Nations (15 February 2011) *List of issues prior to the submission of the fifth periodic report of Australia* (CAT/C/AUS/5), http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fAUS%2fQ%2f5&Lang=en, accessed 4 October 2014.

³ United Nations (9 January 2014) *Consideration of reports submitted by States parties under article 19 of the Convention pursuant to the optional reporting procedure: Fourth and fifth periodic reports of States parties due in 2012 Australia*, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fAUS%2f4-5&Lang=en, accessed 4 October 2014.

⁴ Senate of Australia (2013) *Involuntary or coerced sterilisation of intersex people in Australia*, report of the Community Affairs References Committee, http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_S

aspects of current clinical practice “*disturbing*”, including interpolations of issues relating to sex assignments at birth in decision making around cancer risk and, and also material showing the lack of objective data on what constitutes “*normal*” female genitalia.

The Committee made recommendations to change clinical practices, but the report has not been implemented to date. Human rights violations to “*normalize*” the genitals of infants and children with intersex variations continue.

UN statements on the forced treatment of intersex persons

Report of the Special Rapporteur on Torture

The UN Special Rapporteur on Torture stated on 1 February 2013 in *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Juan E. Méndez:

76. ... There is an abundance of accounts and testimonies of persons being denied medical treatment, subjected to verbal abuse and public humiliation, psychiatric evaluation, a variety of forced procedures such as sterilization, State-sponsored forcible ... hormone therapy and genital-normalizing surgeries under the guise of so called “reparative therapies”. These procedures are rarely medically necessary, can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma (A/HRC/14/20, para. 23).

77. Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, “in an attempt to fix their sex”, leaving them with permanent, irreversible infertility and causing severe mental suffering...

79. The mandate has noted that “members of sexual minorities are disproportionately subjected to torture and other forms of ill-treatment because they fail to conform to socially constructed gender expectations.”⁵

The Special Rapporteur on Torture calls on member states to:

88. The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, “reparative therapies” or “conversion therapies”, when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups.

UN agencies joint statement on involuntary sterilisation

In May 2014, the World Health Organization, the Office of the High Commissioner for Human Rights, UN Women, UNAIDS, UNDP, UNFPA and UNICEF issued a joint statement on *Eliminating forced, coercive and otherwise involuntary sterilization*. The statement covers intersex people, trans people, women, women with HIV, indigenous and ethnic minority women, and people with disabilities.

This is an important development that recognizes a lack of information given to parents and

[terilisation/Sec_Report/index](#), accessed 25 October 2013.

⁵ OHCHR (1 February 2013) *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Juan E. Méndez, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf, accessed 7 February 2013.

individuals, and (in many cases) a weak evidence basis. It states:

Intersex persons may be involuntarily subjected to so-called sex-normalizing or other procedures as infants or during childhood, which, in some cases, may result in the termination of all or some of their reproductive capacity. Children who are born with atypical sex characteristics are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved... As a result, such children are being subjected to irreversible interventions that have lifelong consequence for their physical and mental health...

Medical procedures that might result in sterility may sometimes be justified because of benefits to health, including the reduction of cancer risk... Such treatments may be recommended for transgender or intersex persons; however, they may be proposed on the basis of weak evidence, without discussing alternative solutions that would retain the ability to procreate... Parents often consent to surgery on behalf of their intersex children, including in circumstances where full information is lacking⁶

The report recommends full, free and informed consent:

It has been recommended by human rights bodies, professional organizations and ethical bodies that full, free and informed consent should be ensured in connection with medical and surgical treatments for intersex persons... and, if possible, irreversible invasive medical interventions should be postponed until a child is sufficiently mature to make an informed decision, so that they can participate in decision-making and give full, free and informed consent... It has also been recommended that health-care professionals should be educated and trained about bodily diversity as well as sexual and related biological and physical diversity, and that professionals should properly inform patients and their parents of the consequences of surgical and other medical interventions.

Senate Committee reports on involuntary or coerced sterilisation

An Australian Senate Community Affairs References Committee inquiry into the *Involuntary or coerced sterilisation of people with disabilities in Australia* led to publication of two reports in 2013; one on people with disabilities, and a second on intersex people. The report on the *Involuntary or coerced sterilisation of intersex people in Australia* was published in October 2013. It encapsulates the medical approach, notes evolving rationales for surgical interventions, and the human rights impact:

3.5 ... intersex physiology is considered within the medical community as a medical condition with little or no consideration of the individual.

3.6 An emphasis on removing difference, and thus obscuring intersexuality, is evident in historical medical practice. The rationale for 'normalising' surgery, and the social and medical support for surgical gender assignment, has changed over time.

3.81 'Normalising' surgery on infants and children has the potential to impact on a range of interrelated human rights, including the right to privacy (which extends to the right to personal autonomy/self-determination in relation to medical treatment); the right to equality and non-discrimination; and the prohibition against torture and other cruel, inhuman and degrading treatment (including the prohibition against non-consensual scientific or medical experimentation).⁴

The report noted that intersex infants, children and adolescents will typically, increasingly, be able to provide consent as they approach and attain an age of maturity.

⁶ WHO, OHCHR, UN Women, UNAIDS, UNDP, UNFPA and UNICEF (May 2014) *Eliminating forced, coercive and otherwise involuntary sterilization* http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/, accessed 30 May 2014.

Psychosocial rationales for surgery

A 2013 decision-making framework published by the Department of Health in the State of Victoria elaborates psychosocial rationales as follows; they include rationales such as “*reduced opportunities for marriage*” and parental bonding:

- *risk of assigning the ‘wrong’ sex of rearing, meaning a gender that the child will later reject or feel uncomfortable with, potentially leading to depression or other mental health problems*
- *risk that the child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding and associated negative consequences*
- *risk of social or cultural disadvantage to the child, for example, reduced opportunities for marriage or intimate relationships, or reduced opportunity for meaningful employment and capacity to earn an income*
- *risk of social isolation, restrictions or difficulties, for example, caused by embarrassment or social stigma associated with having genitalia that does not match the gender in which the person lives.*⁷

A 2006 clinician group statement also places the rationales for “*psychosocial*” interventions with the parents; rationales included “*minimizing family concern and distress*”.⁸

Clinician submissions to the 2013 Senate inquiry recommend surgery, for example to reduce the size of a child’s clitoris, or “*repair or construction of a urinary outlet to the end of the penis*”:

*The purpose of these procedures is for functional reasons such as to allow a male individual to urinate while standing, and psychosocial reasons such as to allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing.*⁹

In fact, both stated rationales are for “*psychosocial reasons*”. They relate to the individual’s position in a family and in society, and in relation to social expectations of the individual’s role and performance in those environments. A typical surgical intervention on men’s penises referred to in the clinician submission is termed “*hypospadias repair*”.

Clinician submissions acknowledge a lack of evidence for good surgical outcomes for explicitly *cosmetic* (appearance-related) surgeries in these cases, all of which are currently considered “*therapeutic*” in Australia.

Surgical outcomes on newborns and infants may not become apparent until the child becomes a teenager or adult, and will persist for a lifetime – yet there is no long term follow up to adequately assess this, or provide support to affected people. A submission by the Australasian Paediatric Endocrine Group (“*APEG*”) acknowledges “*particular concern regarding sexual function and sensation*” after surgery.

There is limited evidence reporting long-term outcomes of early surgical management for reasons of appearance. The few outcome studies reported have conflicting results of good

⁷ Victoria Department of Health (February 2013) *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, <http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions>, accessed 27 February 2013.

⁸ Houk, Hughes, Ahmed, Lee, Writing Committee for the International Intersex Consensus Conference Participants (2006) *Summary of Consensus Statement on Intersex Disorders and Their Management*, in *Pediatrics*, doi:10.1542.peds.2006-0737, <http://www.pediatrics.org/cgi/doi/10.1542/peds.2006-0737> accessed 21 November 2012.

*and poor outcomes (cosmetic, sexual, or psychological), with particular concern regarding sexual function and sensation.*⁹

Other such statements include:

*...we acknowledge that outcomes related to current approaches remain to be established.*¹⁰

These are clear examples of the cases referenced by the UN Special Rapporteur on Torture, that take place without the informed consent of the persons concerned.

Stigmatising preconceptions and lack of clinician consensus

The Australian Senate Committee acknowledged that surgeries intend to erase intersex traits from individuals – typically in infancy or early childhood:

*3.109 As OII commented, normalisation surgery is more than physical reconstruction. The surgery is intended to deconstruct an intersex physiology and, in turn, construct an identity that conforms with stereotypical male and female gender categories*⁴

Yet the evidence shows that underlying preconceptions are disturbing and stigmatising:

*3.100 What little research exists regarding 'adequate' or 'normal' genitals, particularly for women, raises some disturbing questions...*⁴

The Australian Senate Committee identified research by Jillian Lloyd and others noting “enormous variation” in the size of women’s genitals, but:

*3.101 ... Despite this range, a recent reference work on surgery on intersex patients in infancy refers simply to creating 'a clitoris that is in the right position and of the right size', without any elaboration, or discussion of what that size might be.*⁴

The Committee quoted from research by Welmoed Reitsma *et al* of 210 physicians in the Netherlands in 2009. The scale of this study, significantly larger than any study of intersex patients, examined the dispositions of general practitioners, gynaecologists and plastic surgeons to refer or perform a surgical labia minora reduction. 164 physicians completed the survey, carried out with a “five-point Likert scale appraisal of four pictures showing a vulva, each displaying different sizes of labia minora”.

Questions were posed concerning physicians' personal predisposition to the vulvas, with regard to naturalness, attractiveness (i.e., the extent of appealing), the physician's private ideal (i.e., the overall preference), and what the physician believed to be society's ideal. Skin color, pubic hair growth, potential irregularities, and asymmetries were comparable among the pictures, thereby eliminating potential biases...

*Almost all of the participating plastic surgeons (90.7%; 39/43) and the majority of the gynecologists (58.5%; 24/41) had performed a labia minora reduction procedure in their clinical practice.*¹¹

⁹ Submission of the Australasian Paediatric Endocrine Group (“APEG”) to the Senate Inquiry Into the *Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development*. 27 June, 2013.

¹⁰ Submission of the Royal Children’s Hospital, Melbourne “DSD” team submission to the Senate Inquiry into the *Involuntary or Coerced Sterilization of People with Disabilities in Australia*. July, 2013.

¹¹ W Reitsma, MJ Mourits, M Koning, A Pascal, B van der Lei (2011) *No (wo)man is an island - the influence of physicians' personal predisposition to labia minora appearance on their clinical decision making: a cross-sectional survey*, in *The Journal of Sexual Medicine*, 2011 8(8):2377-2385, doi: 10.1111/j.1743-6109.2011.02321.x, <http://europepmc.org/abstract/MED/21595842>, accessed 21

The survey results indicated:

- *Ninety percent of all physicians believe, to a certain extent, that a vulva with very small labia minora represents society's ideal (2-5 on the Likert scale).*
- *More plastic surgeons regarded the picture with the largest labia minora as distasteful and unnatural, compared with general practitioners and gynecologists.*
- *Irrespective of the woman's labia minora size and the absence of physical complaints, plastic surgeons were significantly more open to performing a labia minora reduction procedure than gynecologists.*
- *Male physicians were more inclined to opt for a surgical reduction procedure than their female colleagues.¹¹*

The biases identified in the study based on physician gender and profession are of very significant concern. The study found that:

the opinions of general practitioners and gynecologists, on the one hand, and those of plastic surgeons, on the other hand, diverge when considering what constitutes a natural-looking and attractive vulva. Moreover, this survey clearly reveals that gender of the physician is a significant influence: male physicians in all specialties are more inclined to perform the surgical procedure, compared with their female colleagues.¹¹

Research indicating unreasonable expectations of normality in men's genital also exists, although no breakdown of survey responses by physician gender is available. In relation to hypospadias repair, a treatment regarded as simply a physical (rather than cultural) necessity by the Australasian Paediatric Endocrine Group, Professor Alice Dreger references a very large German study in 1995¹² that found that:

...urologists have unreasonably strict expectations for penises. These physicians looked at a group of 500 men and found that only 55 percent could be labeled "normal," according to medical standards. Of the 500, fully 225 counted as having hypospadias... The physicians also questioned whether surgical "correction" of hypospadias was necessary, given what they admitted was the "significant complication rate" of "reparative" surgeries—and given these men seemed to have figured out how to use their penises to their own satisfaction.¹³

Alice Dreger notes that only 6 of the 225 men with hypospadias were aware of any physical anomaly.

The Committee also found that there is no consensus in key areas of medical practice about the appropriate clinician management of some intersex cases – and further evidence of the impact of physician's personal characteristics on the gender assignment and treatment of infants and children with intersex variations. The Senate Committee reports on a survey of Australasian Paediatric Endocrine Group (APEG) members in relation to interventions on children with Congenital Adrenal Hyperplasia, stating that:

3.103 ... The results make for sobering reading, and show both a lack of consensus, and the influence on gender assignment of the medical practitioner's age and experiences

August 2013.

¹² Fichtner J, Filipas D, Mottrie AM, Voges GE, Hohenfellner R. (1995) *Analysis of meatal location in 500 men: wide variation questions need for meatal advancement in all pediatric anterior hypospadias cases.* J Urol. 1995 Aug;154(2 Pt 2):833-4. PMID: 7609191, <http://www.ncbi.nlm.nih.gov/pubmed/7609191>

¹³ Alice Dreger (13 February 2014) *Do You Have to Pee Standing Up to Be a Real Man?* at Pacific Standard, The Science of Society, <http://www.psmag.com/navigation/health-and-behavior/pee-standing-real-man-73133/>, accessed 14 February 2014.

3.106 ... [it] highlights a great diversity of opinions amongst doctors, and some extreme geographical variation in medical practice ...

3.107 ... [it] gives detailed insight to the broader issue ... that there is no medical consensus around the conduct of normalising surgery.⁴

It is unacceptable that physician's gender, age, profession or experience can influence the nature of contentious surgical and hormonal interventions on infants and children with intersex variations. The lifelong impact of such surgeries has been noted by the Special Rapporteur on Torture and the joint UN agencies statement on ending forced sterilisation. Nevertheless, surgical and hormonal interventions continue, in the absence of government implementation of the Senate Committee report.

Rationales for involuntary sterilisation of intersex people

The Australasian Paediatric Endocrine Group, in its submission to the Senate Community Affairs Committee inquiry noted that surgery still takes place in Australia for perceived risks of cancer.

We acknowledge that there are clear physical risks associated with some intersex traits, such as a reported higher risk of gonadal cancers. However, sociology professor Georgiann Davis (herself a person with Complete AIS who has been sterilised due to a low risk of cancer) argues:

In actuality, the risks associated with various intersex traits vary substantially from study to study, leaving us to act on (what might be misguided) predictions about health risks rather than scientific facts.¹⁴

It became apparent only during the course of the Senate inquiry that sterilisations no longer routinely take place on women with Complete AIS. However, sterilisations in Australia of people with intersex variations have been established to take place to align the bodies of minors with proposed sex of rearing. Tony Briffa, Vice President of OII Australia and AISSGA spoke to a public hearing of the Senate inquiry on this experience. Tony has Partial Androgen Insensitivity Syndrome (*Partial AIS* or *PAIS*):

"I have a few pages here from my medical records...It says: 'Mother now ready for gonadectomy.' ... The histology reports, which I will also tender, show that they were healthy testes. But there was no Family Court approval. If we are talking about coercion, doctors coerce families, parents, into believing by saying: 'We need to remove these testes because it will make your child normal'.

It has a serious impact on us in terms of our sexual health, our relationships, being able to reproduce, and being different. One of the things that they say to us is that we need to have our gonads removed because we are different— 'We want to make you look normal.' Of course, part of the whole sterilisation thing is that you have pretty big surgery and scars, so they are making you different! ... [and surgery is] usually over the summer holidays, so your summers are spent in hospital. I am a twin ... I have a non-identical twin sister. She does not have AIS. So I have a perfect example of someone who is normal and someone who is nothing like normal. Following the castration surgery I had scars. Anything like swimming lessons or camping was out. It did not happen.¹⁵

¹⁴ Georgiann Davis (2013) *The Social Costs of Preempting Intersex Traits*, in *The American Journal of Bioethics*, 13:10, 51-53, <http://dx.doi.org/10.1080/15265161.2013.828119>, accessed 11 September 2013.

¹⁵ Parliament of Australia (April 2013) *Transcript of hearing of Community Affairs References Committee, Involuntary or coerced sterilisation of people with disabilities in Australia, Senate of Australia, Community Affairs References Committee, Thursday, 28 March 2013*,

The Senate inquiry heard statements from a “group of medical experts” that demonstrates the overlapping nature of decision making processes. They stated (paragraph 4.27 of the Senate report):

In any individual with a DSD condition, the decision to perform gonadectomy is reached by weighing benefits and risks of various issues, such as risk for [germ cell tumour], sex of rearing, estimated capacity of the gonad to produce hormones in accordance with or opposite to sex of rearing and/or (developing) gender identity, likelihood of gender dysphoria later in life, etc.

The statement 'In case of PAIS, 17α-HSD, and ovotestis, the decision regarding gonadectomy is largely determined by sex of rearing' should be interpreted in this broader and clinically oriented context⁴

In its final report published in October 2013, the Senate Community Affairs References Committee acknowledged that decision making around sterilisations is not value-neutral, and may be influenced not only by cancer risk:

- *4.28 ... The complexity and diversity of cancer risk can become oversimplified, potentially elevating the perceived or communicated risk. Alternative monitoring options may be overlooked.*
- *The committee is concerned that other matters such as 'sex of rearing' or 'likelihood of gender dysphoria' are interpolated into the discussion of cancer risk. This confusion between treatment options to manage cancer risk and treatment options to manage intersex could undermine confidence in the neutrality of those advocating for surgical interventions.*

4.39 ... clinical intervention pathways stated to be based on probabilities of cancer risk may be encapsulating treatment decisions based on other factors, such as the desire to conduct normalising surgery... Treating cancer may be regarded as unambiguously therapeutic treatment, while normalising surgery may not. Thus basing a decision on cancer risk might avoid the need for court oversight in a way that a decision based on other factors might not. The committee is disturbed by the possible implications of this...⁴

The Committee determined that it does not favour current practice in this matter:

4.42 ... The committee does not favour the status quo.⁴

The current distinction between therapeutic and non-therapeutic treatment has failed many intersex people in Australia; it does not satisfactorily distinguish between medically necessary and non-necessary interventions.

The need for change

The Australasian Paediatric Endocrine Group submission to the Senate inquiry concludes:

4. APEG recognises that there are ongoing difficult decisions regarding genital surgery in minors with DSD raised female, specifically regarding reduction in size of the clitoris/phallus i.e., at what degree of ambiguity is surgery indicated and when is the best time to perform such procedures? It will not be possible to legislate on this matter.⁹

However, the Senate Community Affairs References Committee took a different approach:

6.30 ... The medical understanding of intersex is so strongly focussed on binary sex and gender ... Enormous effort has gone into assigning and 'normalising' sex: none has gone

<http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:%22committees/commsen/86ba4480-36ef-4e72-b25e-9fa162f9a4ae/0000%22>, accessed 8 July 2013.

*into asking whether this is necessary or beneficial. Given the extremely complex and risky medical treatments that are sometimes involved, this appears extremely unfortunate.*⁴

The Committee commented directly on the circular relationship between stigma and intervention, and also on the timing of irreversible medical treatments:

3.128 ... Normalising appearance goes hand in hand with the stigmatisation of difference...

There is frequent reference to 'psychosocial' reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child's avoidance of harassment or teasing, and the child's body self-image, there is great danger of this being a circular argument that avoids the central issues...

*Irreversible medical treatment, particularly surgery, should only be performed on people who are unable to give consent if there is a health-related need to undertake that surgery, and that need cannot be as effectively met later, when that person can consent to surgery.*⁴

The Committee agreed with proposals by OII Australia regarding genital surgery:

*3.129 ... The proposals put forward by Organisation Intersex International have merit, and are consistent with the committee's conclusions. The committee believes that a protocol covering 'normalising' surgery should be developed, and then adhered to in all cases of intersex children. Such a guideline should be consistent with Organisational Intersex International's recommendations, particularly 4, 5 and 6.*⁴

Those recommendations for guiding surgery are (in 3.114):

- 1. Medical intervention should not assume crisis in our difference, nor normalisation as a goal.*
- 2. Medical, and in particular surgical, interventions must have a clear ethical basis, supported by evidence of long term benefit.*
- 3. Data must be recorded on intersex births, assignments of sex of rearing, and of surgical interventions.*
- 4. Medical interventions should not be based on psychosocial adjustment or genital appearance.*
- 5. Medical intervention should be deferred wherever possible until the patient is able to freely give full and informed consent; this is known as "Gillick competence".*
- 6. Necessary medical intervention on minors should preserve the potential for different life paths and identities until the patient is old enough to consent.*
- 7. The framework for medical intervention should not infantilise intersex, failing to recognise that we become adults, or that we have health needs as adults.*
- 8. The framework for medical intervention must not pathologise intersex through the use of stigmatising language.*
- 9. Medical protocols must mandate continual dialogue with intersex organisations.*⁴

Early medical interventions have a lifelong impact, including trauma, repeat and reparative surgeries and, in any cases of sterilisation, a lifelong need for hormone treatment.

The AIS Support Group Australia similarly supports a moratorium on non-urgent medical intervention, along with full disclosure and fully informed consent. In place of irreversible and largely cosmetic genital surgeries and hormonal interventions on infants, both intersex-led organizations argued in favour of a focus on family support and counselling, including support from peer groups. No jurisdiction in Australia yet has a policy framework that supports this approach. Informed consent is not possible without this.

Intersex girls and women, and the Convention Against Torture

Current policies governing the practice of Female Genital Mutilation do not adequately protect intersex girls and women from involuntary or coercive surgeries.

In 2013, the Attorney General's Department published a review of legal frameworks around Female Genital Mutilation ("FGM"). It describes FGM in terms that apply to all clitoral surgeries, including those on intersex girls and women:

5.1.33 Female genital mutilation—definition

In this Division, female genital mutilation means: (a) a clitoridectomy; or (b) excision of any other part of the female genital organs; or (c) infibulation or any similar procedure; or (d) any other mutilation of the female genital organs.

The review found such surgeries abhorrent:

Female genital mutilation is an abhorrent practice. It intentionally alters and causes harm to female genital organs for no medical reason and can have serious and long-lasting consequences, including infertility, an increased risk of childbirth complications, and maternal and infant mortality during and shortly after childbirth.¹⁶

However, there are two exemptions where such mutilation is permitted:

5.1.36 Exception—medical procedures for genuine therapeutic purposes

(1) It is not an offence under this Division to perform a medical procedure that has a genuine therapeutic purpose...

(2) The fact that a procedure is performed as, or as part of, a cultural, religious or other social custom is not to be regarded as a genuine therapeutic purpose.

5.1.37 Exception—sexual reassignment procedures

...

(2) A sexual reassignment procedure means a surgical procedure to give a female, or a person whose sex is ambivalent, the genital appearance of a particular sex (whether male or female).¹⁶

These exemptions explicitly permit "*therapeutic*" surgeries on intersex infants, those with "*ambivalent*" sex, i.e. children with intersex variations diagnosed during infancy.

The outcomes of infant genital surgeries on intersex infants – with "*particular concern about sexual function and sensation*" are no different from the outcomes of genital mutilation on girls. Some of the surgeries are identical. The settings for such surgeries are irrelevant; female genital mutilation is considered no less abhorrent if it is carried out by a doctor. The exemptions from protection against female genital mutilation do not permit procedures for cultural purposes:

5.1.36 Exception—medical procedures for genuine therapeutic purposes ...

(2) The fact that a procedure is performed as, or as part of, a cultural, religious or other social custom is not to be regarded as a genuine therapeutic purpose.¹⁶

However, the 2006 clinician group statement on the management of intersex conditions, which is the basis for the 2013 Victorian Health Department decision making framework on the treatment of intersex infants and children, explicitly cites cultural, social ("*psychosocial*")

¹⁶ Attorney General of Australia (24 May 2013) *Review of Australia's Female Genital Mutilation legal framework – Final Report*, <http://www.ag.gov.au/Publications/Pages/ReviewofAustraliasFemaleGenitalMutilationlegalframework-FinalReportPublicationandforms.aspx>, accessed 30 May 2013.

rationales for surgery. The latter includes the rationales “*reduced opportunities for marriage*”, and “*embarrassment or social stigma*”⁷. These are cultural and social rationales.

A principle of non-discrimination must apply. Intersex girls should receive the same protection from mutilation that non-intersex girls receive. That is, any proposed treatment to modify the appearance of genitals should wait until the patient can personally give fully informed consent.

7. Disclosure, privacy and custody

Intersex persons have diverse physical sex characteristics, with consequential issues of disclosure and privacy. These issues are of particular concern in relation to communal spaces, places of detention and body scans.

Intersex children and adults have diverse bodily characteristics, regardless of any prior surgical or hormonal interventions. Many intersex people have obviously different physical characteristics, however it is unhelpful to assume that people with intersex variations will have obvious differences to gender norms. Often times, intersex differences will not be apparent even unclothed. Portraying the needs of intersex persons as a matter of gender assignment is reductive and inappropriate.

Nevertheless, communal bathrooms and change rooms can be a difficult space for some people with intersex variations regardless of gender assignment. Problems in these spaces are often stated as a reason for childhood “*normalizing*” surgeries and hormone treatment, but surgery does not make someone ‘normal’, and consequential scarring and/or trauma can be a significant social barrier.

Custody and detention situations, police and border protection searches and other security scans can provide sources of great discomfort, inappropriate and unnecessary questioning, and inappropriate service delivery. Persons with intersex variations who are in custody must be housed in respectful environments that protect their dignity, and ensure their safety and wellbeing. Providers must maintain access to healthcare and any medication, and support the privacy and dignity of persons with intersex variations.

Diverse physical characteristics create added concerns around security scans and strip searches. Intersex persons must have the right to privacy at all times, and must have the elect the gender of any officer conducting any physical search or clinical tests. Alternative methods of detecting contraband should be employed.

National legislation recognizing intersex status

The Australian government recognises intersex status, alongside other attributes such as sexual orientation and gender identity, in the *Sex Discrimination Act 1984*, as amended in 2013. In February 2013, the Senate’s Legal and Constitutional Affairs Committee stated on the Exposure Draft of the 2012 *Human Rights and Anti-Discrimination Bill* that it supported the creation of an attribute called “*intersex status*”, distinct from a previously proposed “*gender identity*” attribute:

7.16 The committee received considerable evidence regarding the coverage of intersex status in the Draft Bill. The committee recognises that intersex individuals are often the subject of discrimination in public life, and that as such there is a need for protection on the basis of intersex status in Commonwealth anti-discrimination law.

7.17 The committee agrees with the evidence presented by Organisation Intersex International Australia, and other submitters, that intersex status is a matter of biology

*rather than gender identity, and as such should not be covered within the definition of gender identity in the Draft Bill...*¹⁷

From 1 August 2013, the *Sex Discrimination Act* (“SDA”) was amended to include three new attributes: sexual orientation, gender identity and intersex status. In contrast to the other new attributes, intersex status is a biological attribute rather than an identity or orientation:

intersex means the status of having physical, hormonal or genetic features that are:
(a) neither wholly female nor wholly male; or (b) a combination of female and male; or
*(c) neither female nor male.*¹⁸

Intersex status is explicitly not defined in the Act as a third gender or sex, nor is it defined as a gender identity or disability. Intersex is explicitly not a third gender classification:

*15. The definition recognises that being intersex is a biological condition, not a gender identity. It does not require a person who is intersex to identify as either male or female in order to access protections under the SDA. The definition is not intended to create a third sex in any sense. It does, however, recognise that sex is not a binary concept and that an intersex person may have the biological attributes of both sexes, or lack some of the biological attributes considered necessary to be defined as one or other sex.*¹⁹

The Act was accompanied by guidelines that provide for recognition of intersex and other persons with gender identities as men, women, or “X”. It is essential that service provision meets standards established by the *Sex Discrimination Act* and 2013 *Guidelines on Recognition of Sex and Gender*²⁰. Providers must ensure the non-discriminatory treatment of intersex persons. The government should develop standards to ensure dignity and privacy in custodial situations, detention and security scanning.

¹⁷ Senate of Australia, Legal and Constitutional Affairs Committee (February 2013) *Exposure Draft of the Human Rights and Anti-Discrimination Bill 2012*, http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed%20inquiries/2010-13/antidiscrimination2012/report/index, accessed February 2013.

¹⁸ ComLaw (2013) *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013*, <http://www.comlaw.gov.au/Details/C2013A00098>, accessed 22 April 2014.

¹⁹ *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013, Explanatory Memorandum*, p. 12.

²⁰ Attorney General’s Department (2013) *Australian Government Guidelines on the Recognition of Sex and Gender*, <http://ag.gov.au/Publications/Pages/AustralianGovernmentGuidelinesontheRecognitionofSexandGender.aspx> accessed 1 July 2013.