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**For intersex human rights, information, and peer support**

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## **Submission to Australian Law Reform Commission inquiry on Equality, Capacity and Disability in Commonwealth Laws**

### **1. Introduction**

Intersex is a term which relates to a range of natural biological traits or variations that lie between “male” and “female”. 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 the other sex. Intersex is always congenital and can originate from genetic, chromosomal or hormonal variations. It is a relatively widely understood umbrella term for a large number of variations such as Androgen Insensitivity Syndrome (AIS), 5 alpha Reductase (5aRD), Congenital Adrenal Hyperplasia (CAH), 47,XXY (sometimes called Klinefelter Syndrome), complex Hypospadias, Gonadal Dysgenesis, Vaginal Agenesis, Mayer-Rokitansky-Küster-Hauser syndrome (MRKH). We recognise too that not every intersex person has a clear aetiological diagnosis as the genetic basis of every intersex variation is not yet understood<sup>1</sup>.

Intersex people are medicalised, stigmatised and suffer discrimination due to our distinctive biological characteristics. Intersex variations affect perceptions of our realness as men or women, and society still generally requires people to live and identify as male or female. As a result, intersex bodies do not meet societal expectations and intersex people experience homophobia and prejudice.

Organisation Intersex International Australia Limited (OII Australia) is a national body by and for intersex people. We promote the human rights and health of intersex people in Australia, and provide information, education and peer support. OII Australia is a Public Benevolent Trust with Deductible Gift Recipient status. It is funded entirely out of the voluntary contributions of its members. OII Australia employs no staff and receives no public funding.

In this submission, we make a series of recommendations based on items in the Inquiry’s Issues Paper. We then provide material on international and Australian policy and clinical practice, to support our recommendations.

In 2013, the Senate Community Affairs References Committee conducted an inquiry into the involuntary or coerced sterilization of people with disabilities in Australia. The terms of reference included intersex people. We make extensive reference in this submission to the report of that inquiry, and to clinician submissions to that inquiry.

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<sup>1</sup> Olaf Hiort (June 2013) *I-03 DSDnet: Formation of an open world-wide network on DSD* at clinician conference, “4th I-DSD Symposium”: “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](http://www.gla.ac.uk/media/media_279274_en.pdf), accessed 1 July 2013.

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## 3. Recommendations

### Framing principles

The World Health Organization (WHO) defines “disabilities” as:

*...an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.*

*Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.<sup>2</sup>*

The WHO definition applies directly to intersex, in that the medical profession regards intersex people as having an impairment (a “disorder”) in body function or structure known as “disorders of sex development” or “DSD”, sometimes also referred to as “disorders of sexual development”. These “disorders” are regarded as impairments in our body structures (genitals, gonads, chromosomes) or functions (adrenal glands, gonads, mammary or other glands). Some intersex variations are accompanied by specific lifelong health concerns. For example, congenital or iatrogenic infertility, and associated lifelong need for HRT, is common. Some intersex variations are associated with cognitive differences, or developmental issues.

The framing principles developed by the ALRC, “*dignity; equality; autonomy; inclusion and participation; and accountability*” must therefore be applied explicitly to the situation of intersex people in Australia, and not simply via intersectionalities between people with disabilities and other groups.

### Health care and aged care; LGBTI people

From the Inquiry’s Issues Paper<sup>3</sup>:

<sup>2</sup> World Health Organization (WHO) (2013) *WHO | Disabilities*, <http://www.who.int/topics/disabilities/en/>, accessed 5 February 2013.

<sup>3</sup> Australian Law Reform Commission (November 2013) *Equality, Capacity and Disability in*

*Question 34. What issues arise in relation to health care that may affect the equal recognition before the law of people with disability and their ability to exercise legal capacity? What changes, if any, should be made to Commonwealth laws and legal frameworks relating to health care to address these issues?*

*242. Another significant issue relating to consent to medical treatment is involuntary or coerced sterilisation of girls and women with disability, and of intersex people... Sterilisation of intersex people is reportedly undertaken to 'normalise' them and to clinically treat 'disorders of sexual development'. However, this has raised significant concerns.*

We are pleased that the Inquiry has noted the sterilisation and normalisation of intersex people in the Issues Paper.

*245. In the second report of the Senate Committee on the involuntary or coerced sterilisation of intersex people, the Committee recommended that all medical treatment of intersex people take place under guidelines that support deferral of normalising treatment until the person can give fully informed consent. The Senate Committee also recommended authorisation by a court or tribunal for the 'complex and contentious' medical treatment of intersex people who are unable to make decisions for their own treatment.*

*310. Lesbian, gay, bisexual, transgender and intersex (LGBTI) people with disability often face intersectional discrimination and may have to disclose both their sexual orientation, gender identity or intersex status as well as their disability, resulting in what has been referred to as a 'second coming out'. Broadly, the social exclusion and isolation as well as mental health issues which are experienced by many LGBTI people may be exacerbated for those who also have disability, and access to services which cater for the needs of LGBTI people with disability can be difficult...*

*312. In the context of health and medical treatment, key issues arise in relation to: recognition and involvement of same-sex partners for the purposes of consent and medical decision making; HIV/AIDS; and involuntary medical interventions involving intersex people which may affect their long-term health and wellbeing, such as sterilisation.*

We note that “*intersex people who are unable to make decisions for their own treatment*” are typically infants, children or adolescents who will be able to provide consent, if treatment is deferred until they are older.

OII Australia participated in the Senate inquiry and seeks implementation of the recommendations made by the Community Affairs References Committee. In particular:

- Surgeries not required to meet physical needs must be deferred until such time as the affected person can freely provide fully informed consent if they wish to undergo treatment. A consent-based model should be adopted for physical and psycho-social care, ensuring the full participation of affected individuals, such that all children who can be expected to develop capacity are able to provide fully informed consent.
- Treatment to manage cancer risk must be disambiguated from psychosocial issues, such as those associated with sex of rearing.
- Counselling, information and support must be provided to families and affected persons, including by intersex-led peer support and systemic advocacy organisations. Priority should be given to intersex-led organisations to avoid replicating models that stigmatise intersex variations and non-conforming gender expression.
- Medical interventions must take place within a national human rights-based policy framework, and with proper scrutiny.

- Research into long term outcomes must be supported, including through community-based schemes.
- Prenatal hormone treatment for CAH must be regulated, or preferably discontinued.

Regarding legal scrutiny of medical interventions on intersex people:

- We have not been able to find any legal case related to an intersex infant, child or adolescent where treatment proposed by doctors was refused by a court. This includes a case referenced in 2013 by the Chief Justice of the Family Court where sterilisation was proposed simply to align a person's body with a changed sex of rearing (after earlier clitorrectomy in line with previous sex of rearing). Given this analysis, we believe that legal scrutiny is no substitute for a human rights-based national policy framework for intersex-related medical intervention and non-intervention.
- In the absence of a national treatment policy framework, intersex-related medical interventions must be subject to legal scrutiny within a human rights framework.

Additionally, we recommend:

- Intersex girls must no longer be excluded from legislation and regulation that prohibits Female Genital Mutilation.
- Criminal sanctions should also apply to surgical or hormonal interventions that do not adhere to an agreed national policy framework.

## Intimate relationships; LGBTI people

The Issues Paper states:

*278. Many people with disability may be denied the right to engage in intimate relationships, in part as a result of the attitudes of support staff, agency policies that prohibit sexual relations and an aggressive risk management culture in many support agencies. There may also be a directive from parents or family members to the residential facility to prohibit this for their adult child regardless of the person's wishes and their adult status.*

*279. People with disability who live in group homes or institutions, and lesbian, gay, bisexual, transgender and intersex people with disability face particular difficulties.*

We are unclear about the inclusion of intersex persons in paragraph 279, given that the statement seems predicated on issues around same sex relationships. Intersex people are not *ipso facto* participants in same sex relationships.

However, intersex persons may be addressed, or treated in a demeaning manner or in voyeuristic ways by health care workers and/or other personnel in institutional settings, due to physical sex characteristics.

From the Issues Paper:

*313. Another issue many LGBTI people with disability face is discrimination and prejudice around their right to engage in intimate relationships. This issue is exacerbated in institutional settings where carers and support staff may not be appropriately trained or aware of issues arising for LGBTI people.*

We find it unhelpful to use the term "*LGBTI*" in this context, as it presumes that issues around same sex intimate relationships are *ipso facto* relevant to intersex people, when intersex persons are understood to participate in as diverse a range of relationships as non-intersex persons. Given such misconceptions, we believe that it is vital for the Australian Law Reform Commission to gain an understanding of intersex issues through discussion with intersex-led

From the Issues Paper

*314. Finally, the operation of religious exemptions under anti-discrimination legislation has been highlighted by members of the LGBTI community as being particularly problematic where disability, health, aged care and other services are provided by religious organisations.*

We note that the Sex Discrimination Act, as amended in 2013, does not contain religious exemptions applicable to intersex people. Lack of awareness of this provision in anti-discrimination legislation is, however, a significant cause for concern. It creates a misunderstanding that such discrimination is acceptable, and may even create possibilities for occurrences of such discrimination.

#### 4. International context

While intersex is not specifically mentioned in international law, international institutions have, in recent years, begun to address intersex health and human rights issues.

##### Report of the Swiss National Advisory Commission on Biomedical Ethics

The Swiss National Advisory Commission on Biomedical Ethics published a globally significant document on intersex in November 2012<sup>4</sup>. It is notable for a range of reasons:

- It makes a clear apology for damage done to intersex people in the past, and up until the present.
- It makes a case for criminal sanction for non-medically necessary genital surgeries.
- It makes a strong case against medical intervention solely for “*psychosocial*” reasons.

We present some of the findings of the Commission on “*psychosocial*” rationales for medical intervention. The emphasis is the Commission’s:

***Epecially delicate are those cases where a psychosocial indication is used to justify the medical urgency of surgical sex assignment in children who lack capacity. Here, there is a particularly great risk of insufficient respect being accorded to the child’s (future) self-determination and its physical integrity...***

***Decisions on sex assignment interventions are to be guided by the questions of what genitalia a child actually requires at a given age (apart from a functional urinary system) and how these interventions will affect the physical and mental health of the child and the future adult. Treatment needs to be carefully justified, especially since – in functional, aesthetic and psychological respects – surgically altered genitalia ... are not comparable to natural male or female genitalia.***

*Decisions are to be guided, above all, by the child’s welfare...*

*The harmful consequences may include, for example, loss of fertility and sexual sensitivity, chronic pain, or pain associated with dilation (bougienage) of a surgically created vagina, with traumatizing effects for the child. **If such interventions are performed solely with a view to integration of the child into its family and social environment, then they run counter to the child’s welfare.** In addition, there is no guarantee that the intended purpose (integration) will be achieved.*

Further, the Commission states:

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<sup>4</sup> Swiss National Advisory Commission on Biomedical Ethics (November 2012) *On the management of differences of sex development, Ethical issues relating to “intersexuality, Opinion No. 20/2012”*, available in English via <http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en> accessed 21 November 2012.

*...on ethical and legal grounds, all (non-trivial) sex assignment treatment decisions which have irreversible consequences but can be deferred should not be taken until the person to be treated can decide for him/herself*<sup>Error! Bookmark not defined.</sup>

## Report of the UN 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."<sup>5</sup>

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 sterilization

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 recognises the lack of information given to parents and 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*

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<sup>5</sup> 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](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf), accessed 7 February 2013.



*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 lacking*

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<sup>6</sup>*

## Council of Europe Resolution

In October 2013, the Council of Europe, a 47-member country institution that oversees human rights, pharma and many other issues across those countries, adopted a resolution on the protection of children's rights to physical integrity. Resolution 1952 (2013) includes a specific statement on intersex. Section 2 reads:

*2. The Parliamentary Assembly is particularly worried about a category of violation of the physical integrity of children, which supporters of the procedures tend to present as beneficial to the children themselves despite clear evidence to the contrary. This includes, amongst others, female genital mutilation, the circumcision of young boys for religious reasons, early childhood medical interventions in the case of intersexual children and the submission to or coercion of children into piercings, tattoos or plastic surgery.*

The Council calls for member countries to:

*7.5. take the following measures with regard to specific categories of violation of children's physical integrity:*

and subsection 7.5.3 itemises those measures, including this subsection:

*7.5.3. undertake further research to increase knowledge about the specific situation of intersex people, ensure that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support;*

## Statement of Council of Europe Human Rights Commissioner

In May 2014, the Council of Europe's Commissioner for Human Rights issued a powerful statement on the rights of intersex people. It acknowledges a history of surgeries without consent, and our rights to self-determination and physical integrity. It acknowledges a need for greater public awareness, and better support for parents, families and intersex children:

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<sup>6</sup> 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/](http://www.who.int/reproductivehealth/publications/gender_rights/eliminating-forced-sterilization/en/), accessed 30 May 2014.

*“Corrective” operations and treatment are usually traumatising and humiliating. They can take a long time and post-operative complications are common. There are long-term effects on intersex individuals’ mental health and well-being... early “normalising” treatments do not respect intersex persons’ rights to self-determination and physical integrity. Intersex babies and younger children are not in a position to give their consent. The proxy consent given by parents may not be free and fully informed and can hardly take into account the best interests of the child in the long-run.<sup>7</sup>*

It also acknowledges the need for better legal recognition – and makes reference to Australia’s reform of the Sex Discrimination Act, describing it as “a powerful tool to foster the equality of intersex people”. Muižnieks concludes:

*I urge governments in Europe to review their current legislation and medical practices to identify gaps in the protection of intersex people and take measures to address the problems. Policy makers should involve civil society advocates of intersex persons such as the OII Europe and ILGA-Europe in these efforts. The enjoyment of human rights is universal and it cannot depend on the sex of the person. Intersex individuals must be granted full legal recognition from birth*

## 5. Legal recognition of intersex in Australia

Recognition of intersex status, alongside other attributes such as sexual orientation and gender identity, is made in several new areas of law and regulation.

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 the previously proposed “gender identity” attribute:

*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. Further, the committee considers that the current requirement in the Draft Bill that intersex individuals identify as either male or female is misguided, and is unhelpful for intersex individuals whose biological characteristics do not necessarily accord with a male or female identification.<sup>8</sup>*

From 1 August 2013, the *Sex Discrimination Act* 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:

*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.<sup>9</sup>*

Intersex status is explicitly not defined as a third gender or sex, nor is it defined as a gender identity or a form of disability. Intersex is explicitly not a third gender classification<sup>10</sup>. Regarding religious exemptions, the Explanatory Memorandum to the then bill states:

<sup>7</sup> Council of Europe Commissioner for Human Rights (9 May 2014) *A boy or a girl or a person – intersex people lack recognition in Europe* <http://humanrightscomment.org/2014/05/09/a-boy-or-a-girl-or-a-person-intersex-people-lack-recognition-in-europe/>, accessed 9 May 2014.

<sup>8</sup> 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](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed%20inquiries/2010-13/antidiscrimination2012/report/index), accessed February 2013.

<sup>9</sup> 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.

<sup>10</sup> Parliament of Australia (2013) *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013, Explanatory Memorandum*, p. 12.



*The Bill will extend the exemption at section 38 of the SDA, so that otherwise discriminatory conduct on the basis of sexual orientation and gender identity will not be prohibited for educational institutions established for religious purpose. Consequently, the Bill will not alter the right to freedom of thought, conscience, and religion or belief in respect of the new grounds of sexual orientation and gender identity.*

*The Bill will not extend the exemption to cover the new ground of intersex status. During consultation, religious bodies raised doctrinal concerns about the grounds of sexual orientation and gender identity. However, no such concerns were raised in relation to 'intersex status'. As a physical characteristic, intersex status is seen as conceptually different. No religious organisation identified how intersex status could cause injury to the religious susceptibilities of its adherents. Consequently, prohibiting discrimination on the basis of intersex status will not limit the right to freedom of thought, conscience and religion or belief.<sup>11</sup>*

The 2013 Australian Government Guidelines on the Recognition of Sex and Gender define intersex as follows:

*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 the other sex. Intersex is always congenital and can originate from genetic, chromosomal or hormonal variations. Environmental influences such as endocrine disruptors can also play a role in some intersex differences. People who are intersex may identify their gender as male, female or X.<sup>12</sup>*

The guidelines roll out a standard procedure for the recording and alteration of gender markers across Commonwealth departments and agencies. They also roll out a third classification, X, previously available on passports.

The Aged Care (*Living Longer Living Better*) Act 2013 recognises “lesbian, gay, bisexual, transgender and intersex people” as a special needs category, alongside other groups such as “people from culturally and linguistically diverse backgrounds”, “veterans”, “people who are financially or socially disadvantaged”.<sup>13</sup>

This legal and regulatory framework shows that intersex people exist in Australia, and we are a clearly defined category of persons with specific needs. The simultaneous creation of three new attributes, sexual orientation, gender identity, and intersex status, was not accidental; all three communities of interest experience discrimination due to our failure to conform to social norms of sex and gender. Our inclusion in the Sex Discrimination Act owed much not only to our identification as a group of people suffering stigmatisation and discrimination on grounds of our intersex status, but also to increasing awareness of our existence and our contributions to society.

## 6. Clinical practices in Australia

Intersex people are medicalised, stigmatised and suffer discrimination due to our distinctive biological characteristics. Intersex variations affect perceptions of our realness as men or women, and society still generally requires people to live and identify as male or female. As a

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<sup>11</sup> Parliament of Australia (2013) *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013 – Explanatory Memorandum*  
[http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22legislation%2Fems%2Fr5026\\_ems\\_1fcd9245-33ff-4b3a-81b9-7fdc7eb91b9b%22](http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22legislation%2Fems%2Fr5026_ems_1fcd9245-33ff-4b3a-81b9-7fdc7eb91b9b%22), accessed 7 July 2013.

<sup>12</sup> 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.

<sup>13</sup> ComLaw (2013) *Aged Care (Living Longer Living Better) Act 2013*,  
<http://www.comlaw.gov.au/Details/C2013A00076> accessed 22 April 2014.

result, intersex bodies do not meet societal expectations and intersex people experience homophobia and prejudice.

Intersex persons may be addressed, or treated in a demeaning manner or in voyeuristic ways by health care workers and/or other personnel in institutional settings, due to our physical characteristics<sup>14</sup>. The Victorian Equal Opportunity and Human Rights Commission has introduced some guidelines for general practitioners in this matter<sup>15</sup>.

The Senate inquiry on involuntary or coerced sterilisation of intersex people in Australia noted that interventions on intersex people differ from contentious interventions on many people with disabilities in that intersex infants, children and adolescents will typically be able to consent after attaining age of maturity.

*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).*

The inquiry also noted “no consensus in key areas of medical practice”, but surgical interventions continue today:

*3.53 There was a view among intersex support groups and representative organisations that medical practice has not materially evolved since Money's theories were first endorsed, and that normalising surgery remains a standard response to intersex conditions. OII Australia submitted that rationales for normalisation surgery remain based on psychosocial theories that give primacy to the perceived need for others to see intersex people as 'normal':*

*Current protocols in Australia are still based on psychosocial adjustment: minimising family concern, and mitigating the risks of stigmatisation due to physical difference.<sup>66</sup>*

*3.54 The National LGBTI Health Alliance agreed, submitting that normalising procedures are 'a standard medical practice in Australia and elsewhere today'.*

## **2006 medical “Consensus statement” and 2013 Victorian guidelines**

The Prader scale<sup>16</sup> divides visible genitalia into seven categories, with male and female categories at either end which are considered “normal”. The current protocols for the treatment of intersex people are laid out in a 2006 *Consensus Statement on Intersex*

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<sup>14</sup> Advocates for Informed Choice (10 December 2012) *Report to the UN Special Rapporteur on Torture: Medical Treatment of People with Intersex Conditions as Torture and Cruel, Inhuman, or Degrading Treatment or Punishment*, <http://aiclegal.org/wordpress/wp-content/uploads/2012/10/AIC-Testimony-to-the-United-Nations-Special-Rapporteur-on-Torture-December-2012.pdf> accessed 14 December 2012.

<sup>15</sup> Victorian Equal Opportunity and Human Rights Commission (January 2014) *Guidelines for General Practitioners* [http://www.humanrightscommission.vic.gov.au/media/k2/attachments/General\\_Practices\\_Guideline\\_for\\_web.pdf](http://www.humanrightscommission.vic.gov.au/media/k2/attachments/General_Practices_Guideline_for_web.pdf), accessed 25 January 2014.

<sup>16</sup> Eunice Kennedy Shriver National Institute of Child Health and Human Development (USA) (undated) *Prader Scale*, [https://science.nichd.nih.gov/confluence/download/attachments/23920688/Prader\\_Scale.pdf](https://science.nichd.nih.gov/confluence/download/attachments/23920688/Prader_Scale.pdf), accessed 6 February 2013.

*Disorders and Their Management*. Until the 2006 *Consensus Statement*, all genitals that did not conform to male or female norms were surgically altered so that they cosmetically appear “normal”. From 2006, the *Consensus Statement* advises surgery:

*in cases of severe virilisation (Prader III, IV, and V)*

That is, in 3 of those 7 Prader Scale stages, surgery intended to make an infant’s genitalia cosmetically appear “normal” is still considered appropriate. If such surgeries were undertaken on, for example, infant girls with “normally” sized clitorises, then our society would consider that to be “female genital mutilation”.

The 2006 *Consensus Summary Statement* includes the following rationales for “early reconstruction” (that is, cosmetic surgeries on the genitals of infants) as:

*“minimizing family concern and distress”*  
*“mitigating the risks of stigmatization and gender-identity confusion”.*<sup>17</sup>

A 2013 decision-making framework published by the Victoria Department of Health elaborates psychosocial rationales as follows:

- *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.*<sup>18</sup>

Medical interventions based on psychosocial rationales do not relate to any necessary intervention required for physical reasons, such as the ability to urinate. Rather, they relate to the individual’s position in a family and in society, and in relation to social expectations of the individual’s role in those environments.

The guidelines also make judgements about the risk of a wrong decision in relation to future gender identity:

*For example, for some intersex conditions, there is a material risk that the gender assigned at birth will be inconsistent with the person’s gender identity in future. In these conditions, there could be a significant risk of making a wrong decision about a treatment such as irreversible surgery to make the patient’s genitals look consistent with the norms of their assigned gender.*

*For other conditions, where there is more certainty about future gender identity, the risk of making a wrong decision about such surgery would be less significant.*

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<sup>17</sup> 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.

<sup>18</sup> 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.

Irreversible surgery to make patients' genitals "*look consistent with the norms of their assigned gender*" is still the standard protocol where there is "*more certainty about future gender identity*". This includes treatment in cases of 45,XX Congenital Adrenal Hyperplasia, where the identified rate of changes in gender assignment are just under 10%<sup>22</sup>.

OII Australia's opposition to genital confirming treatments on intersex infants and children is not based on future gender identity, but on the lack of evidence of good outcomes, particularly in relation to post surgical sexual function and sensation, the non-medically necessary nature of such surgeries, and the lack of attention to the child's human rights.

## Sterilisations

The Australasian Paediatric Endocrine Group (APEG), in its submission to the Senate Community Affairs Committee inquiry noted that surgery still takes place in Australia for the following:

a. *Surgery for cancer risk...*

Sterilisations of intersex people in Australia have also been established to take place to align the bodies of minors with proposed sex of rearing. The Senate inquiry heard from a "*group of medical experts*" that demonstrates the overlapping nature of decision making processes:

*4.27 ... 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, 17 $\alpha$ -HSD, and ovotestis, the decision regarding gonadectomy is largely determined by sex of rearing' should be interpreted in this broader and clinically oriented context*

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...*

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

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

In her submission<sup>19</sup> to the Senate inquiry on involuntary or coerced sterilisation, the Chief Justice of the Family Court referenced *In the Matter of the Welfare of a child A* (1993) FLC 92-402 (per Mushin J). The case is instructive<sup>20</sup>.

5. *At the time of A's birth he was diagnosed as suffering from a condition known as congenital adrenal hyperplasia...*

9. *The application which is made by the mother seeks authorisation from the court that A be permitted to undergo bilateral mastectomies, a hysterectomy and oophorectomy...*

10. *The background for this is well expressed by the surgeon. His report, to the extent that it is relevant, is in the following terms:*

*Following investigation after birth, this child was correctly assessed as being a genetic female with an extreme degree of masculinization. The degree of masculinization is variable and depends on the severity of the original abnormality in the adrenal gland. In some children this is mild and in others it is severe. However, in all cases it would be standard medical practise (sic) to raise the child as a female with a potential for normal female fertility. The genitalia are therefore operated on in the postnatal period to make them feminine in appearance. This advise (sic) and treatment was carried out in (A's) early years and she had genital reconstruction to give her a feminine appearance. She was also given cortisone hormone treatment to replace the absent hormone and prevent any further masculine hormones being produced by the abnormal adrenal gland...*

12. *Further in that report the endocrinologist states:*

*As (A's) endocrinologist, I consider her to be completely male in her outlook due to the prenatal and postnatal exposure to excessive levels of adrenal androgen. I do not believe that this situation is reversible. If a satisfactory operation to make male genitalia can be performed, I believe that (A) should have it...*

13. *I am critical of both the parents, and particularly the mother, that the treatment recommended by the doctors at the time of the A's birth was not pursued. It appears on the basis of the material which is available to me that had that treatment been undertaken it may well have been possible to avoid the appalling situation which has now arisen and in respect of which I am asked to make this decision.*

14. *...A has already had suicidal thoughts arising directly out of the very ambiguous situation in which he finds himself.*

We summarise the situation as follows:

- The case describes an individual aged 14¾ who was treated since infancy under the standard “*therapeutic*” protocol for their 46,XX CAH diagnosis (this remains the standard protocol today).
- The “*psychosocial*” therapeutic rationale for treatment involved a clitorrectomy/removal of phallus, and irreversible genitoplasty during infancy, to give a “*feminine appearance*”.
- In other 46,XX children this would commonly be described as “*female genital mutilation*”.
- The child was suicidal.

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<sup>19</sup> The Hon. Diana Bryant AO, Chief Justice of the Family Court of Australia (2013) submission #36 on the senate inquiry on involuntary sterilization of people with disabilities.

<sup>20</sup> Family Court of Australia (1993) *Welfare of A Child A* Between: Mother Applicant and the Public Advocate Respondent Number of Pages - 6 [1993] FamCA 68; (1993) FLC 92-402 16 Fam Lr 715 Children (30 June 1993), <http://www.austlii.edu.au/au/cases/cth/FamCA/1993/68.html>, accessed 26 February 2013.



- The case was brought before the court to provide for surgeries to enable the child to live as male, i.e. the original sex-of-rearing assignment, and the postnatal surgery “*to make them feminine in appearance*” were inappropriate.
- Reassignment was given to require sterilisation through oophorectomy, even though there’s no evidence that this was necessary to enable male sex of living.
- The judge in the case expressed no critical evaluation of the validity of the medical protocol put forward in this case nor more generally; the standard therapeutic protocol was regarded as unremarkable. Why was the prior assessment of the child as female ‘correct’ in the face of the case under review?
- The judge was egregious in criticism of the parents in an assertion that they had “*failed*” to properly suppress androgen production through postnatal medication, as if this might have an impact. We find the blame attracted to the mother to be particularly abhorrent. It is strongly implied (in point 13) that the child’s self assessed gender identity was a consequence of this. We are unaware of any evidence to support this, while the evidence on adult gender identities refutes such simplistic arguments. Researchers and clinicians Kuhnle and Krahl state:

*Is culture or society imposing a certain gender role, or do individuals shape their own gender roles? The few available case reports, including our own, seem to indicate that intersex individuals find their own gender independent and maybe even undisturbed by external factors*<sup>21</sup>

- The case was brought by the mother, not clinicians involved in the case.
- This case was endorsed by the Chief Justice through her discussion of it in her 2013 submission to the Senate.

As the infant genital surgery described is considered “*therapeutic*”, it did not need to go before the Family Court.

Child A’s circumstances are not unusual. While it remains the standard protocol for 46,XX CAH children to undergo the same “*therapeutic*” treatment, around 10% of these children will go on to identify as male. Furtado, who has stated that “*between 8.5–20% of individuals with DSDs*” go as far as to permanently change their gender assignment, also stated that “*[e]arly surgery seems to be a safe option for most*” patients with CAH – even while acknowledging that around one in ten cases with that diagnosis have been shown to change gender assignment<sup>22</sup>.

The therapeutic treatment applied in infancy this case, endorsed by the Chief Justice, is by no means universally held.

The Swiss National Advisory Commission on Biomedical Ethics published a globally significant document on intersex in November 2012 which went as far as recommending:

*Recommendations*

*12. There should be a legal review of the liability implications of unlawful interventions in childhood, and of the associated limitation periods. Questions of criminal law, such as the applicability of offences of assault (Art. 122 and 123, StGB) and the prohibition on genital mutilation (Art. 124, StGB), should also be investigated.*<sup>4</sup>

The UN Special Rapporteur on Torture found that structural inequalities between patients and doctors create structural inequalities:

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<sup>21</sup> Kuhnle and Krahl (2002) *The Impact of Culture on Sex Assignment and Gender Development in Intersex Patients*, in *Perspectives in Biology and Medicine*, volume 45, number 1 (winter 2002):85–103, The Johns Hopkins University Press.

<sup>22</sup> Furtado, P. S. et al. (9 October 2012) *Gender dysphoria associated with disorders of sex development*, in *Nat. Rev. Urol.* doi:10.1038/nrurol.2012.182, <http://www.nature.com/nrurol/journal/vaop/ncurrent/abs/nrurol.2012.182.html>, accessed 2 March 2013

*29. ... Structural inequalities, such as the power imbalance between doctors and patients, exacerbated by stigma and discrimination, result in individuals from certain groups being disproportionately vulnerable to having informed consent compromised.*<sup>23</sup>

It is our view that this case demonstrates the failure of the Family Court to identify or manage structural inequalities that impact directly on the lives of intersex people in Australia. The case shows, to us, that the court system operates in a self-referential manner, consulting the adults already involved in a decision without the skills or expertise to question the data it is supplied. There are no contradictors, no human rights-based framework to manage interventions, and no patient advocates from the intersex community involved in the decision making process.

The impact of the initial surgical intervention (not taking into account later surgeries following Family Court assent) is lifelong. Given this analysis and impact, we believe that legal scrutiny is no substitute for a human rights-based national policy framework for intersex-related medical intervention.

### Genital surgeries and hormone treatment

Medical interventions seek to erase intersex differences. The Australasian Paediatric Endocrine Group (APEG), in its submission to the Senate Community Affairs Committee inquiry noted that surgery still takes place in Australia for the following:

- a. Surgery for cancer risk...*
- b. Surgery for dysfunctional urine flow...*
- c. Surgery for creation of a vagina...*

*Surgery may be performed to create a vagina where there was none present at birth. This surgery also involves separating the labial/scrotal folds which may be fused together, but no removal of tissue.*

- d. Reconstructive reduction of an enlarged 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 for 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. Surgery for psychosocial indications remains in contention both within Australasia and internationally, particularly for reduction of an enlarged clitoris, as tissue is being removed which the individual may wish was not removed later on.*

Recognition of the contentious nature of these surgeries is absent from public statements by Professor Sonia Grover of the Royal Children's Hospital, Melbourne. Professor Grover is part of the hospital's specialist team working with intersex patients and families, alongside two of the four authors of the APEG submission, Professor Garry Warne and Dr Jacqueline Hewitt.

On 20 June *The Age* reported a view – and a direct quote – by Professor Grover demonstrating absolute medical certainty:

*The Royal Children's Hospital Melbourne currently performs one or two gonadectomies a year on infants with undescended testes... The hospital also performs 10 to 15 genital reconstruction operations a year often on girls under the age of two.*

*Associate Professor Sonia Grover, director of the department of gynaecology at the Royal Children's Hospital, says studies show girls with CAH would identify as females and want*

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<sup>23</sup> 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](http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf), accessed 7 February 2013.

*to have periods and sex later in life and that surgery done early produced good results. All infant surgery is conducted with the informed consent of parents.*

*"While we have the data to say they are going to end up identifying as females ... and we have evidence that surgical outcomes are good, and sensory outcomes and sexual function are good, where's the pressure to change the practice?" Grover says.<sup>24</sup>*

In contrast, APEG suggests that there is conflicting evidence on outcomes with “*particular concern*” around sexual function. The group gives the following recognition of the limited evidence for surgical intervention:

*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 and poor outcomes (cosmetic, sexual, or psychological), with particular concern regarding sexual function and sensation. Surgical techniques have differed over time, with clitorectomy no longer performed, and clitoral reduction now being favoured by surgeons.... there is a lack of strong evidence to either support or refute specific recommendations on timing.*

The Royal Children’s Hospital, Melbourne, in its submission to the Senate inquiry also supported surgical interventions, even while:

*...we acknowledge that outcomes related to current approaches remain to be established. (RCH<sup>25</sup>, p.7)*

The profoundly conflicting opinions provided by different members of the same specialist team at the Royal Children’s Hospital are a matter of deep concern to us.

We take the phrasing around “conflicting results” ... “*with particular concern regarding sexual function and sensation*” to confirm what we have seen reported in Schützmann<sup>26</sup> and elsewhere (detailed in our second submission), that such outcomes are poor. With surgical rationales that are intrinsically focused on genital appearance, this is completely unsurprising. Properly informed consent should fully reflect these “*conflicting results*” and “*particular concern*”, not an assertion of certainty.

We note that hormonal interventions are also made:

*For girls with a specific diagnosis of congenital adrenal hyperplasia there can be spontaneous reduction in the size of the clitoris with adequate hormone replacement therapy*

Irreversible hormone treatment is also faced by minors with 47,XXY (an extra sex chromosome), including HRT from puberty, typically without any associated counselling or support. Indeed, the standard diagnosis of Klinefelter Syndrome in cases of 47,XXY presumes a male gender identity, and we are aware of concerns that the masculinity of such adolescents is so fragile that it should not be questioned.

We are concerned at the implications of iatrogenic (medically induced) changes on puberty and future gender identity. We believe that the problematisation of physical sex-related non-conformity is itself the problem. In our view, statements made by APEG reflect societal

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<sup>24</sup> The Age (20 June 2013) *It takes more than two*, <http://www.theage.com.au/national/it-takes-more-than-two-20130619-2oj8v.html>, accessed 20 June 2013.

<sup>25</sup> Royal Children’s Hospital, Melbourne (July, 2013) Submission by the “DSD” team submission to the Senate Inquiry into the Involuntary or Coerced Sterilization of People with Disabilities in Australia.

<sup>26</sup> Schützmann, K. et al. (February 2009) *Psychological Distress, Self-Harming Behaviour, and Suicidal Tendencies in Adults with Disorders of Sex Development*, in *Archives of Sexual Behaviour* 38(1):16- 33, <http://link.springer.com/article/10.1007%2Fs10508-007-9241-9>, accessed 7 February 2013

norms and perceived roles that perpetuate gender inequalities and the rigid application of societal sex norms that are unwarranted in their application to children. This is evidenced by its statement supporting:

*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*

The APEG submission 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*

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

The report recommendations included:

*Recommendation 3*

*3.130 The committee recommends that all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour deferral of normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons.*

*Recommendation 5*

*4.43 In light of the complex and contentious nature of the medical treatment of intersex people who are unable to make decisions for their own treatment, the committee recommends that oversight of these decisions is required.*

*Recommendation 6*

*5.30 The committee recommends that all proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court.*

The committee acknowledges that surgeries intend to erase intersex traits from individuals – typically in infancy or early childhood – and society, yet the underlying preconceptions are disturbing and stigmatising:

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

*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*

*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.*

The committee agree with our proposals 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.*

Those recommendations for guiding surgery, accepted by the committee, 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.*

In place of appearance-related genital surgeries on infants, the priority should focus on family support and counselling. No jurisdiction in Australia yet has a policy framework that supports all of these guidelines.

OII Australia believes that surgeries that do not meet these conditions must cease. In line with the recommendations in the Senate report, we propose a human rights-based national policy framework for intersex-related medical interventions on intersex people.

The federal government has not yet made a formal response to the report, which remains to be implemented.

### **Australian policy regarding Female Genital Mutilation**

Cultural, familial and medical attitudes towards our differences from sex norms govern which sex we are assigned, and what surgical and other medical interventions will be made to ensure we conform to those norms. In 2013, the Attorney General's Department published a review of legal frameworks around Female Genital Mutilation ("FGM"). It is defined as follows:

#### *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.*<sup>27</sup>

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).*

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

We believe that the outcomes of infant genital surgeries on intersex infants 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.*

However, the 2006 Consensus 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*”) rationales for surgery.

The Victorian Health Department also describes these social risks, in terms that might equally apply to women who have not undergone female genital mutilation in societies where that is the norm, such as marriageability, social and cultural disadvantage and social stigma:

- *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.*<sup>28</sup>

The Australasian Paediatric Endocrine Group (APEG), in its submission to the Senate Community Affairs Committee inquiry noted that surgery still takes place in Australia for the

<sup>27</sup> 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.

<sup>28</sup> Victoria Health Department (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.

*d. Reconstructive reduction of an enlarged 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 for 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. Surgery for psychosocial indications remains in contention both within Australasia and internationally, particularly for reduction of an enlarged clitoris, as tissue is being removed which the individual may wish was not removed later on.*

Surgery to change the appearance of the genitals of intersex girls and other infants is not medically necessary; it's considered socially and culturally necessary. In relation to rationales focusing on "genitalia incongruous with the sex of rearing", we note the growing social recognition of the existence and rights of transgender children; while such children do not face medical intervention until they can provide consent, social transition is increasingly supported.

Kuhnle and Krahl (2002) found, in research in Malaysia, that the sex assignment of intersex infants varied not simply based on their diagnosis but also the culture of their parents and the position of women in that culture.

*...we would like to analyze briefly the cultural and ethnic differences of the three races living in Malaysia and present some data which in our opinion illustrates the different ways in which intersex patients are accepted.<sup>21</sup>*

*The ethnic Malay women are Muslims... the independence and the economic power of Malay women can be substantial... The condition of women is quite different in the ethnic Indian and Chinese communities... In neither culture or tradition were women able to inherit or control their own fortune... Among the Indian community girls usually mean a significant financial burden to the family, since depending on the social status of the family a significant dowry is expected, and to marry off several girls can be a financial disaster. In contrast, boys will increase the family's fortune<sup>21</sup>*

The outcome of such cultural norms for intersex infants is thus:

*While we were working with different ethnic groups, it was never difficult to convince a Muslim family to assign a severely virilized girl or an undervirilized boy to the female gender. This was not the case for Chinese and Indian families, who on several occasions took off with their ambiguously born child when female sex assignment (or reassignment) was suggested.*

The treatment of intersex infants in both Malaysia and Australia is just as culturally-based and specific as arguments that support female genital mutilation. It is simply the case that it can be difficult to objectively observe our own cultural norms.

We believe that genital surgeries on intersex infants to give them the appearance of a specific sex are just as mutilating as identical surgeries on girls. In our view, the different language used to describe such surgeries reflects a degree of cultural relativism and double standards.

Intersex infants should receive the same protection from mutilation that girls receive. That is, any proposed treatment to modify the appearance of genitals should wait until the patient can personally give fully informed consent.

OII Australia does not accept that an exemption for intersex girls from policy frameworks on FGM is warranted. The policy framework criminalizing FGM must include intersex girls.