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Submission on intentional self-harm and suicidal behaviour in children

1. OII Australia

Organisation Intersex International Australia Limited (OII Australia) is a national body by and for intersex people. We promote the human rights of intersex people in Australia, and provide information, education and peer support. OII Australia is a not-for-profit company, recognised by the Australian Taxation Office as a charitable Public Benevolent Institution. OII Australia employs no staff and receives no public funding; this means that we have limited capacity to respond to inquiries except those of high significance to our community. Nevertheless, we thank the National Children's Commissioner for conducting this consultation on self-harm and suicidal behaviour in children; and we warmly welcome the opportunity to make a submission.

2. Contents

3. Intersex

In this submission we use the term intersex rather than the controversial clinical term "*Disorders of Sex Development*" or "*DSD*"; this is in line with Australian legislation and regulations that recognise intersex status, and a Senate Community Affairs References Committee report that acknowledges that intersex is not intrinsically a disorder.

Intersex is not about gender identity; intersex people have a broad range of gender identities. There are intersex men, women, both men and women, neither, and non-binary people. It is likely, however, that most non-binary people are not intersex. Intersex is a lived experience of the body.

Many forms of intersex exist; it is a spectrum or umbrella term, rather than a single category. It 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).

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

Intersex people have non-heteronormative bodies, bodies that affect perceptions of our realness as men or women. Intersex people are born with atypical physical sex characteristics, including genetic, hormonal and anatomical differences. Intersex bodies do not meet societal expectations. A medical paper published this year still describes an intersex birth as a "*challenging clinical emergency*"[1]. Cultural, familial and medical attitudes govern to which sex we are assigned. Surgical and other medical interventions are made to ensure we conform to those norm, to erase intersex differences.

This has profound consequences for our physical and mental health, and thus on self-harming and suicidal behaviour in children.

4. Our interests in this inquiry

In Australia, a Senate Community Affairs References Committee report on the *Involuntary or coerced sterilisation of intersex people in Australia* published in October 2013, as well as amendments to the *Sex Discrimination Act* that became law on 1 August 2013, and Commonwealth *Guidelines on the Recognition of Sex and Gender*, reflect growing awareness of an Australian intersex community and our health and human rights issues.

Recommendations:

Implement the recommendations of the Senate Community Affairs References Committee inquiry on the Involuntary or coerced sterilisation of intersex people in Australia.

Establish a non-discriminatory, coherent national human rights-based policy framework for medical interventions on intersex infants, children and adolescents. This framework should be developed in participation with intersex-led organisations.

[1] Pasterski, Mastroyannopoulou, Wright, Zucker (February 2014) *Predictors of Posttraumatic Stress in Parents of Children Diagnosed with a Disorder of Sex Development* in Archives of Sexual Behavior, referenced in *Intersex health and wellbeing: the role of parent counselling in two contrasting studies*. http://oii.org.au/24677/counselling-two-contrasting-studies/, accessed May 2014.

Resource OII Australia and the AIS Support Group Australia to effectively provide peer support and counselling, systemic advocacy and policy development.

Raise awareness of intersex, and bodily diversity issues more broadly, to combat stigma through the development, printing and distribution of information.

5. 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[2]. 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:

> ***Especially 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.*[2]

Further, the Commission states:

> *…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*[2]

[2] 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.

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.*[3]

In relation to the experience of patients, whether or not they go before the courts, the UN Special Rapporteur on Torture comments:

> *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.*[3]

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.*[3]

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*

[3] 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.

> *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 lacking*[4]

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*[4]

Council of Europe Resolution

In October 2013, the Council of Europe, a 47-member country institution that overseas 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.*[5]

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,*

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[4] 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.

[5] Council of Europe (October 2013) *Resolution 1952 (2013) Children's right to physical integrity*, http://www.assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=20174&lang=en, accessed 2 October 2013.

> *guarantee bodily integrity, autonomy and self-determination to persons concerned, and provide families with intersex children with adequate counselling and support;*[5]

Statement of Council of Europe Human Rights Commissioner

In May 2014 Nils Muižnieks, 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:

> *"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.*[6]

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*[6]

6. National legislation and regulatory recognition of intersex status

Sex Discrimination Act

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.*[7]

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[6] 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.

[7] 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.

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.*[8]

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[9].

Recognition of sex and gender

Identification documents are something of a media fixation on intersex issues, and intersex is frequently conflated with a non-binary gender identity. In contrast, Commonwealth recognition has far more clarity. 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.*[10]

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 only on passports.

Birth certificates are a State and Territory matter. In this regard, we note that international best practice regarding identification documents is set out for trans people in the Open Society Foundations report, *Licence to Be Yourself*[11]. It states, "*Options for children and youth should recognize their evolving capacities*" (page 9), and "*From a rights-based perspective, third sex / gender options should be voluntary*" (page 21).

No State or Territory has a policy framework for birth certificates that satisfactorily addresses these two issues, or provides for the full diversity we would wish to see. In March 2014, the ACT government introduced a third classification available from birth, and a loose definition of the term “intersex” that, in our view, is not well suited to birth registration legislation.[12]

In November 2013, the German parliament introduced a de facto blank birth certificate classification for some intersex infants, despite the opposition of all German intersex

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[8] 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.
[9] *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013, Explanatory Memorandum*, p. 12.
[10] 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.
[11] Open Society Foundations (May 2014) *License To Be Yourself* http://www.opensocietyfoundations.org/reports/license-be-yourself, accessed 1 June 2014.
[12] See OII Australia (20 March 2014) *Birth registrations in ACT*, http://oii.org.au/24868/birth-registrations-in-act/ accessed 20 March 2014.

organisations, with one describing media fascination as "silly season fantasies"[13]. In relation to the German birth certificate proposals, OII Australia secretary Morgan Carpenter joined with IVIM/OII Germany's Dan Ghattas and Silvan Agius of ILGA-Europe to write an opinion piece in Der Spiegel pointing out:

> *…no reporter has yet asked how this will effectively improve quality of life for intersex people, particularly when cosmetic genital surgeries on infants are set to continue.*
>
> *… real progress for intersex people is not measured through the number of available labels but through an end to the human rights breaches currently being inflicted.*[14]

7. Senate committee report on involuntary or coerced sterilisation

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).*[24]

The committee acknowledged 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.*[24]

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[13] See OII Australia (20 August 2013) *German proposals for a "third gender" on birth certificates miss the mark*, http://oii.org.au/23183/germany-third-gender-birth-certificates/, accessed 20 August 2013.
[14] Silvan Agius, Morgan Carpenter, Dan Ghattas (22 August 2013) *Third Gender: A Step Toward Ending Intersex Discrimination* in *Der Spiegel*, http://www.spiegel.de/international/europe/third-gender-option-in-germany-a-small-step-for-intersex-recognition-a-917650.html, accessed 22 August 2013.

The committee agreed 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.*[24]

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.

8. Intersex traits and DSD

In 2006, a clinician "consensus statement" replaced the term intersex with Disorders of Sex Development in clinical settings[15]. This has proved controversial ever since, and the term intersex is itself now more widespread than in 2006, as can be seen from recent legislation and regulation.

Scholars in medical sociology have identified that the rationale for a shift in terminology was a reassertion of medical authority in the face of community criticism. Georgiann Davis states:

> *Medical professionals needed to maintain their authority in the face of intersex activism, and they did so linguistically through a reinvention of the intersex diagnosis. The new DSD terminology constructs "sex" as a scientific phenomenon, and a binary one at that...This places intersexuality neatly into medical turf and safely away from critics of its medicalization.*[16]

[15] 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.
[16] Georgiann Davis (2011) "'*DSD is a perfectly fine term": reasserting medical authority through a shift in intersex terminology'*, in *Advances in Medical Sociology*, Vol. 12, 2011, p. 178.

Morgan Holmes states that the terminology shift "*reinstitutionalises clinical power to delineate and silence those marked by the diagnosis*"[17] Georgiann Davis states "*A medical condition is only as real as its definition*"[16]. The significance of terminology is further elucidated by Professor Jeff Nisker in his article *Informed Choice and PGD to Prevent "Intersex Conditions"* in the American Journal of Bioethics. He writes:

> *I began laboratory research on PGD in 1989 to offer an option to Canadian women already undergoing in vitro fertilization (IVF) who carried a gene for a "severe" genetic condition and planned to undergo amniocentesis. However, when our study moved from "the mouse to the human" in 1993 and the press pounced, many couples with no indication for IVF and no inherited risk called my office requesting PGD. The most frequent genetic condition they desired to prevent was XX (they wanted a boy)…*
>
> *Once a difference becomes a medical disorder to which the medical profession is dedicating time and resources to prevent, procedures to this end become endowed with appropriateness*[18]

Behrmann and Ravitsky found it necessary to point out in the same publication:

> *Many – if not most – persons with intersex conditions lead healthy and fulfilled lives.*[19]

Likewise, Davis comments:

> *…many people with intersex traits are leading full and happy lives. In our community you will find an assortment of parents, partners, and folks with vibrant careers. Many have not allowed the shame and stigma to taint their lives. Others have made the intersex trait an important piece of their identity. Some publicly push boundaries about sex and gender (and even sexuality)… what I've found in my research is that a major source of the social and psychological harm originates in the medical profession and could be prevented with open, honest, and accurate communication and information.*[26]

Evidence shows that, in the case of persons with an extra sex chromosome, such as 47,XXY, life expectancy is normal and cases often go undiagnosed[20]. A 2010 Consensus statement on diagnosis and clinical management of Klinefelter syndrome reports "*only 25% of estimated cases are diagnosed post-natally, and <10% are detected at or before birth*".[21] Despite these low rates of diagnosis, termination rates for 47,XXY once diagnosed during pregnancy are known to reach up to 88%.[2223] The framing of this diagnosis as a major

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[17] Morgan Holmes (2011) *The Intersex Enchiridion: Naming and Knowledge in the Clinic*, in *Somatechnics*, Vol. 1(2): 87-114. DOI: 10.3366/soma.2011.0026.
[18] Jeff Nisker (2013) *Informed Choice and PGD to Prevent "Intersex Conditions"* in the *American Journal of Bioethics*, 13:10, 51-53**,** http://dx.doi.org/10.1080/15265161.2013.828119, accessed 11 September 2013.
[19] Jason Behrmann and Vardit Ravitsky (2013) *Queer Liberation, Not Elimination: Why Selecting Against Intersex is Not "Straight" Forward* in the *American Journal of Bioethics*, 13:10, 51-53**,** http://www.tandfonline.com/doi/full/10.1080/15265161.2013.828131, accessed 11 September 2013.
[20] World Health Organization (undated) *Gender and Genetics*, at Genomic resource centre, http://www.who.int/genomics/gender/en/index1.html, accessed 22 April 2014.
[21] A. F. Radicioni, A. Ferlin, G. Balercia, D. Pasquali, L. Vignozzi, M. Maggi, C. Foresta, A. Lenzi (2010) *Consensus statement on diagnosis and clinical management of Klinefelter syndrome* in *Journal of Endocrinological Investigation*, December 2010, Volume 33, Issue 11, pp 839-850
[22] Texas Department of State Health Services (2005) *BIRTH DEFECT RISK FACTOR SERIES: Klinefelter Syndrome,* http://www.dshs.state.tx.us/birthdefects/risk/risk19-klinefelter.shtm, accessed 28 September 2014.
[23] Céline M Girardin, Guy Van Vliet (2011) *Counselling of a couple faced with a prenatal diagnosis of Klinefelter syndrome*, in *Acta Pædiatrica*, Foundation Acta Pædiatrica 2011 100, pp. 917–922, DOI: 10.1111/j.1651-2227.2011.02156.x, http://onlinelibrary.wiley.com/doi/10.1111/j.1651-2227.2011.02156.x accessed 26 April 2014.

genetic disorder thus has a dramatic impact on the percentage of pregnancies carried to term. We believe that this impact far outweighs the largely benign consequences of sex chromosome differences.

This debate about terminology thus has implications that are of direct relevance to this inquiry. The Senate Community Affairs References Committee notes in their 2013 report of an inquiry into the *Involuntary or coerced sterilisation of intersex people in Australia*:

> *2.4 Not everyone who is intersex has a health problem: whether they experience a 'disorder' is not defined by whether they are biologically 'intersex'. A person might have a form of Androgen Insensitivity Syndrome and present as having an uncommon physiology that appears neither completely female nor completely male, and they may or may not experience health issues. As the Swiss National Advisory Commission on Biomedical Ethics put it:*
>
> > *not all cases of DSD involve a (pathological) "disorder", i.e. a functional impairment associated with suffering. Not infrequently, a case of DSD may involve a variation from a norm of sex development which does not require medical treatment. From the perspective of those affected, the term "disorder" may thus appear stigmatizing*[24]

In its recommendations, the Senate Committee stated:

> *Recommendation 1:*
> *"The committee recommends that governments and other organisations use the term 'intersex' and not use the term 'disorders of sexual development"*
>
> *Recommendation 2:*
> *The committee recommends that health professionals and health organisations review their use of the term 'disorders of sexual development', seeking to confine it to appropriate clinical contexts, and should use the terms 'intersex' or 'differences of sexual development' where it is intended to encompass genetic or phenotypic variations that do not necessarily require medical intervention in order to prevent harm to physical health.*[24]

In its rationale for these recommendations, the Senate Committee found that a clinical shift in terminology from intersex to DSD was justified by an assertion of pejorative connotations of the word intersex that are actually a *post hoc* rationalisation:

> *2.16 It concerns the committee that there appears to be no evidence to support the position taken on appropriate terminology by the 2006 'Consensus Statement … The committee has sought to limit its use of the term DSD to those contexts in which therapeutic medical treatment is being discussed by literature that uses the term. In general discussion and in policy documents, the committee endorses the position of the Commonwealth Department of Health and Ageing, the Victorian Department of Health, and Organisation Intersex International, that 'intersex' should be the preferred terminology. This terminology has also now been adopted in Commonwealth Government guidelines to be applied by all Commonwealth agencies.*[24]

We note the evaluations of both the Senate Community Affairs Committee and the Swiss National Advisory Commission on Biomedical Ethics that intersex traits are not intrinsically disordered, and do not necessarily require medical treatment. Intersex traits should not be problematized as Disorders of Sex Development.

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[24] 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_Sterilisation/Sec_Report/index, accessed 25 October 2013.

9. Intersex and concepts of normality

Concepts of normality are subjective, culturally determined, and even impacted by profession and gender.

For example, Welmoed Reitsma *et al* conducted a multi-centre study 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.*[25]

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.*[25]

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.*[25]

Georgiann Davis anticipated the conclusions of the 2013 Senate Community Affairs References Committee report on *Involuntary or coerced sterilisation of intersex people in Australia*. In *The Social Costs of Preempting Intersex Traits*, in *The American Journal of Bioethics* she writes:

> *It is the case that many individuals with intersex traits report substantial social and psychological harms tied to their "abnormalities." However, if one wishes to use the social and psychological harm argument to justify PGD to select against intersex traits, it is important to acknowledge that it is largely, albeit perhaps not exclusively, the medical*

[25] 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 August 2013.

> *field—not the intersex trait itself—that causes such stigmatization and creates the "hostile social environment…*
>
> *Because the medical profession, not the intersex trait itself, is a major source of the social and psychological harm that perpetuates intersex stigmatization and the "hostile social environment" that individuals with inter-sex traits encounter, justifying PGD by pointing to such negative outcomes is ill-advised and a circular logic.*[26]

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[27]. The Victorian Equal Opportunity and Human Rights Commission has introduced some guidelines for general practitioners in this matter:

> *Intersex people are a distinct group from transgender people and may experience different forms of discrimination. This might include:*
>
> - *failure to fully disclose diagnosis details, or doing so in a disrespectful manner or ways that prejudge treatment paths*
> - *failure to fully inform regarding treatment options, risks and outcomes, including options to delay or avoid interventions*
> - *suggesting that they must identify as a specific gender, or must have genital surgery, hormone or other treatment*
> - *irrelevant focus on the sex of the patient, including binary definitions of sex on intake and patient record forms (for example, tick-boxes that only offer two options, 'male' or 'female').*[28]

The increasing social acceptance of lesbians and gay men, and of transgender people, demonstrates that concepts of normality around sex and gender are shifting. Jason Behrmann and Vardit Ravitsky comment:

> *Given current trends toward acceptance of sexual and gender minorities (the "Queer community"), we encourage further reflection regarding intersex minorities whose well-being is not medically questionable but rather dependent on their social inclusion.*[19]

Rapid changes in legislative, regulatory environments and in social acceptance mean that previous clinical assumptions about normality, the impact of stigma and the necessity of clinical intervention are no longer appropriate. From the Senate Committee inquiry:

> *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.*[24]

We do not believe that, as intersex people, we are afflicted, defective or deficient. We believe that intersex traits are a normal human phenomenon, part of the diversity of human experience.

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[26] 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.

[27] 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.

[28] 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, accessed 25 January 2014.

10. Clinical practices in Australia

Intersex people remain 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. Surgical and hormonal interventions take place in all States. 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.66*
>
> *3.54 The National LGBTI Health Alliance agreed, submitting that normalising procedures are 'a standard medical practice in Australia and elsewhere today'.*[24]

2006 medical "Consensus statement" and 2013 Victorian guidelines

The Prader scale[29] 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 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)*[15]

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".*[15]

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*

[29] 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, accessed 6 February 2013.

- *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.*[30]

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.*[30]

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%[46].

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.

The ethical framework behind the Victorian Health Department guidelines published in February this year comes substantially from two papers by Lynn Gillam, Jacqueline Hewitt and Garry Warne, all from RCH. Their 2010 paper was critiqued by Alice Dreger, David Sandberg, and Ellen Feder, in the same publication, *Hormone Research in Paediatrics*.[32]

Warne and Professor Sandberg, Director of the Division of Child Behavioral Health in the Department of Pediatrics and Communicable Diseases at the University of Michigan, were both contributors to the 2006 "Consensus" statement[31], so this critique co-authored by Sandberg of an ethics paper co-authored by Warne represents a very significant difference in interpretation of that document.

Arguments by Dreger, Sandberg and Feder reflect a preference for a focus on psychosocial support, rather than psychosocial rationales for surgery:

> *Many have now recognized that the central challenge in DSD care is not centered on the surgeries per se, but rather finding a way to help families (and healthcare professionals)*

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[30] 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.

[31] Hughes, Houk, Ahmed, Lee, LWPES/ESPE Consensus Group (2006) *Consensus statement on management of intersex disorders*, Archives of Disease in Childhood 2006;000:1–10. doi: 10.1136/adc.2006.098319.

> *overcome the shame and anxious secrecy that may shape minds and force hands in ways that ultimately harm all involved…*[32]

They comment on existence of multi-disciplinary teams that APEG acknowledges don't exist in Australia:

> *The authors appear to assume 'that conditions for good ethical decision-making [...] are already in place'. And yet the environment for shared decision making [5] – the highly integrated, interdisciplinary healthcare team that includes behavioral health services called for in the DSD consensus [2] – that makes possible such good decision-making remains elusive…*

And an ethical approach that is not informed by practice elsewhere:

> *The authors have opted to ignore the existing DSD ethics literature in an effort to arrive at principles putatively unburdened by previous ethical engagement.*[32]

The limited scope for intersex community organisations to participate in the development of the Victorian framework document is evident in its support for customary surgical interventions with psychosocial rationales.

There is, in fact, growing concern and debate about the necessity and ethics of medical intervention within the medical community, as well as the intersex community.

Dr Mika Venhola, a Deputy Chief of the Oulu University Hospital Department of Pediatrics and Adolescence, Finland[33] has recently spoken out on intersex issues. He says that:

> *The treatment paradigm of intersex conditions is debatable and clinicians are in confusion as to the best management of intersex.*[34]

In a video interview, Venhola describes how, from the get go, surgeries on intersex infants "aroused a lot of questions" in his mind:

> *When I was training to become a paediatric surgeon I was taught how to do these, let's say, corrective, in parentheses, "corrective" cosmetic surgeries, and at that time it was not allowed to criticise your elders, and it was impossible to voice out then my expression or thoughts on this one. But when I was doing my first intersex surgery due to cosmetic reasons I felt it was such a huge human rights violation, and especially the children's rights violation, that I swore I will never do this when I am independent and can decide for myself. And I have never done it, since then. It kind of struck me so hard that it is not right…*
>
> *It's time to stop and think... And this is the part of growing up, to see that surgery is not the solution to everything. It is a saying that, "if you give a surgeon a hammer, every problem is a nail". And I'm trying to see the screws also.*
>
> *There are patients that will do much better without surgery. And I as the surgeon do not lose anything there; I don't have to do surgery... [I am] trying to figure out the patients who*

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[32] A Dreger, D Sandberg, E Feder (2010) *Ethical Principles for the Management of Infants with Disorders of Sex Development, in Hormone Research* in Paediatrics, Horm Res Paediatr 2010;74:412–418, DOI: 10.1159/000316940, http://www.karger.com/Article/Pdf/316940, accessed 7 July 2013

[33] See Oulu University Hospital staff page http://www.oulu.fi/pediatr/staff.htm, accessed 13 August 2013.

[34] Mika Venhola (October 2012) "*Intersex: Ambiguous Genitals Or Ambiguous Medicine?*" http://www.nocirc.org/symposia/twelfth/symposium12.pdf, accessed 13 August 2013.

> *benefit from my surgical skills and who are the patients I should not operate, who would do better with some other treatment or no treatment at all*[35]

In a conference statement in October 2012, Venhola stated:

> *..the gender of the [intersex] child is an educated guess and entails a great risk of error. The atypical genitals of babies with intersex conditions are not a health risk but early genital surgery is performed for aesthetic or social purposes. Genital surgery seeks to produce genitals that match the supposed gender of the infant. The advocates of surgery consider this mandatory but controversy exists. Some authorities consider cosmetic surgery on babies as genital mutilation. There are no controlled studies of the efficacy of surgery over conservative and supportive care to enable good sexual function, quality of life, and parental bonding. The techniques of surgery are infested with poor long-time results and redo surgery is very likely.*
>
> *Intersex genital surgery is not without problems. The management of intersex conditions is based on expert opinion, and evidence on proper treatment is lacking. Intersex is also an ethical problem as full disclosure, informed consent, and children's rights are not unquestionably respected.*[34]

He summarises his position thus:

> *Why operate on the child's body if the problem is in the minds of the adults?*[35]

Anne Tamar-Mattis of Advocates for Informed Choice in the US, writing in Psychology Today states:

> *There's a theory floating around the world of medicine that goes like this: while it is widely known that patients with [intersex variations] are unhappy with the treatment they have received – cosmetic genital surgery, unwanted hormone treatment, and humiliating genital exams top the list – they can be safely ignored because there is actually a "silent majority" of patients out there who are doing just fine. This is a comforting idea. It justifies the mistakes of the past, and it allows current practice to continue without all the discomfort of change.*
>
> *... But no one can find them. After almost two decades of patient advocacy and active debate, decades in which hundreds of affected people have spoken out against the treatment they received, not one person ... has spoken out publicly to say that normalizing treatment is just great. Not one.*
>
> *But there is a silent majority out there in the world of DSD treatment. And I have found them. They are the clinicians, the researchers, the junior practitioners, the social workers, the nurses, the psychologists who know or suspect that there is something very wrong with current treatment models, but keep their thoughts to themselves.*[36]

While no senior Australian clinicians have yet felt able to publicly state their concern, we are aware of many individuals who have expressed concern about existing protocols. Chris Somers xxy (currently a board member of OII Australia), Tracy Reibel and David Whyatt of the Combined Universities Centre for Rural Health found evidence of this even amongst primary health care practitioners in remote WA, interviewed in 2006 and 2007. A midwife comments:

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[35] Bonobo3D (8 April 2013) Transcription of *Paediatric Surgeon Mika Venhola on INTERSEX*, on YouTube, http://www.youtube.com/watch?v=riNtxjntqZE&feature=youtu.be, accessed 12 April 2013.
[36] Anne Tamar-Mattis (30 October 2012) *The Dex Diaries, Part 9: The Real Silent Majority*, at *Psychology Today*, http://www.psychologytoday.com/blog/fetishes-i-dont-get/201210/the-dex-diaries-part-9-the-real-silent-majority, accessed 7 February 2013.

> *Surgical intervention... I don't think that should be done. I would not think that would be an immediate priority. ... The problem with surgical intervention is once it's done, you can't change your mind 12 years later, when this child suddenly shows far more traits of being female and um, well, no probably more the other way, showing far more traits of being male, and you have taken away everything, that could enhance some sort of maleness in this child. So I think personally I would leave surgical, I wouldn't touch surgical not as a child... even if the genetics were all saying 'boy' or all saying 'girl; I still think that it is something that as an infant, I don't think that is all that important; because it is physical, and it is not going to change the way a baby or a small child is going to be. And it is irreversible and you cannot do anything about it.*[37]

A paediatrician, in relation to a 46,XX CAH infant suggested unspecified minimal surgery, but recognised the irreversible nature of such surgeries and the inability to identify the future gender of an infant with ambiguous genitalia:

> *You have already done irreversible surgery so you can't go backward, and at the same time you have made somebody a boy and then she thinks she could have been better off as a girl, you can't go back. That's why they say that the best approach and in my opinion and that within society is you do minimal surgery and give that gender assignment in childhood and then wait until the child himself is between sixteen to eighteen…*[37]

Others remained unaware that cosmetic genital surgeries on infants still take place; this is a social worker:

> *… my understanding is that that the medical profession does not do gender reassignment surgery on young babies anymore because of the adverse affects it has had on adults...* [37]

In our view, the limited awareness of current medical protocols has helped to perpetuate them. Limited public awareness also perpetuates stigma and shame.

We are also aware of some intersex people who have come to terms with the surgeries performed on them as infants or children; this is a beneficial psychological state, however this is distinct from the notion of being happy with the treatment received. The impact of non-necessary sterilization or genital surgeries, for example, remain lifelong.

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…*[38]

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 Androgen Insensitivity Syndrome 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.*[26]

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[37] Chris Somers xxy, Tracy Reibel and David Whyatt (2008) *Intersex and Androgyny And Implications for Provision of Primary Health Care*. Geraldton, WA: Combined Universities Centre for Rural Health. Available on http://www.curch.uwa.edu.au

[38] Submission of the Australasian Paediatric Endocrine Group 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.

Sterilisations of intersex people in Australia have also been established to take place to align the bodies of minors with proposed sex of rearing. Tony Briffa, Vice President of OII Australia spoke to a hearing of the Senate Inquiry on this experience. Tony has Partial Androgen Insensitivity Syndrome:

> *"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.*[39]

The Senate inquiry heard from a "*group of medical experts*" that demonstrates the overlapping nature of decision making processes. They stated (paragraph 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, 17α-HSD, and ovotestis, the decision regarding gonadectomy is largely determined by sex of rearing' should be interpreted in this broader and clinically oriented context*[24]

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*

[39] 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*, 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.

> *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…*[24]

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

> *4.42 … The committee does not favour the status quo.*[24]

OII Australia believes that the current distinction between therapeutic and non-therapeutic treatment has failed many intersex people in Australia.

Congenital Adrenal Hyperplasia

Postnatal and prenatal treatment for intersex traits is deeply entangled with issues of possible non-typical gender identity, gender expression and sexual orientation.

A 1990 peer-reviewed article by Heino Meyer-Bahlburg entitled, *Will Prenatal Hormone Treatment Prevent Homosexuality?* appeared in the Journal of Child and Adolescent Psychopharmacology. Meyer-Bahlburg considered how research on intersex differences could be used to explore the potential "*prenatal hormone screening or treatment for the prevention of homosexuality*"[40]. While his research showed the "*scientific groundwork*" to be "*insufficient*" at that time, prenatal screening and treatment of intersex traits continues.

In 2010, Professors Alice Dreger and Ellen Feder, with lawyer Anne Tamar-Mattis reported[41] on a 1999 clinical paper by Meyer-Bahlburg that problematizes the gender expression and sexual orientation of people with CAH:

> *CAH women as a group have a lower interest than controls in getting married and performing the traditional child- care/housewife role. As children, they show an unusually low interest in engaging in maternal play with baby dolls, and their interest in caring for infants, the frequency of daydreams or fantasies of pregnancy and motherhood, or the expressed wish of experiencing pregnancy and having children of their own appear to be relatively low in all age groups.*[42]

This research on CAH involves use of a steroid, dexamethasone, to modify the behaviour, gender expression and physical expression associated with CAH; dexamethasone has no impact on associated adrenal gland insufficiency, so prenatal treatments are aimed at cosmetic and social adjustment only, not the serious health consequences associated with adrenal insufficiency and salt wasting.

In 2010, a paper constructed "*low interest in babies and men – and even interest in what they consider to be men's occupations and games – as "abnormal," and potentially preventable with prenatal dex*". The quoted paper reads:

> *Gender-related behaviors, namely childhood play, peer association, career and leisure time preferences in adolescence and adulthood, maternalism, aggression, and sexual orientation become masculinized in 46,XX girls and women with 21OHD deficiency [CAH].*

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[40] Heino Meyer-Bahlburg (1990) *Will Prenatal Hormone Treatment Prevent Homosexuality?* in Journal of Child and Adolescent Psychopharmacology, 1990/1991, 1(4): 279-283. doi:10.1089/cap.1990.1.279. http://online.liebertpub.com/doi/abs/10.1089/cap.1990.1.279 accessed 12 July 2013.

[41] Alice Dreger, Ellen K. Feder, Anne Tamar-Mattis (2010) *Bioethics Forum blog - Preventing Homosexuality (and Uppity Women) in the Womb?* At Hastings Center Bioethics Blog, http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4754, accessed 18 May 2012.

[42] H. F. L. Meyer-Bahlburg (1999) *What Causes Low Rates of Child-Bearing in Congenital Adrenal Hyperplasia?* in *The Journal of Clinical Endocrinology & Metabolism*, Volume 84 Issue 6 | June 1, 1999, http://press.endocrine.org/doi/full/10.1210/jcem.84.6.5718, accessed 18 May 2012.

> *These abnormalities have been attributed to the effects of excessive prenatal androgen levels on the sexual differentiation of the brain and later on behavior… We anticipate that prenatal dexamethasone therapy will reduce the well-documented behavioral masculinization.*[41]

We note that hormonal interventions are also made prenatally and postnatally. APEG state:

> *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*[38]

Taking note of the risks and experimental nature of prenatal hormone treatment for CAH, the Senate Committee recommended:

> *Recommendation 14*
> *6.25 The committee recommends that the Commonwealth government investigate the appropriate regulation of the use of dexamethasone for prenatal treatment of CAH.*
>
> *Recommendation 15*
> *6.27 The committee recommends that, effective immediately, the administration of dexamethasone for prenatal treatment of CAH only take place as part of research projects that have ethics approval and patient follow-up protocols.*[24]

We are not aware of any clinical acknowledgement or implementation of these recommendations.

As differing forms of sex and gender non-conformity, sexual orientation, gender identity, gender expression and intersex status are clearly closely intertwined. Indeed, our understanding of prenatal treatments for CAH leads us to recognize prenatal and postnatal treatments as based upon heteronormative expectations of future identity and behaviour, as well as expectations of different social roles for men and women. Behrmann and Ravitsky comment:

> *While Sparrow draws stark distinctions between sex, gender, and sexual orientation, these concepts are actually intertwined on many levels. Parental choice against intersex may thus conceal biases against same-sex attractedness and gender nonconformity.*[19]

OII Australia believes that it is unethical to treat or select on the basis of sex, sexual orientation, gender identity, gender expression or intersex status.

In the Matter of the Welfare of a child A

It is a matter of concern to us that, in her submission to the Senate inquiry on Involuntary or coerced sterilisation, the Chief Justice utilised a misquoted medical term and repeatedly encloses the term “intersex” within quotation marks, implying that it has no legal, community or other standing:

> *I understand that the Committee’s terms of reference were expanded on 7 February 2013 to include references to “intersex people”. I will make some concluding comments about the sterilisation of people with disorders of sexual [sic] development”…*[43]

It is our view that this gives a demonstration of the UN Special Rapporteur on Torture’s “structural inequality” resulting in a partisan, disparaging use of language, and no critical evaluation of the validity or efficacy of medical protocols.

In her submission[43] 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[44].

> *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.*[44]

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 clitorectomy/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*".

[43] 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.
[44] 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 child was suicidal.
- 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 presumed to require sterilisation through oophorectomy, even though there is 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*[45]

- 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[46].

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.*[2]

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[45] 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.

[46] 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

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.*[38]

Recognition of the contentious nature of these surgeries is absent from public statements attributed to 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 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.*[47]

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.*[38]

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*[48]*, 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 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.

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 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*[38]

Claims of improved surgical techniques

Both the RCH DSD submission and the Victorian health guidelines imply or claim an improvement in surgical techniques:

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[47] 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.
[48] 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.

> *…we acknowledge that outcomes related to current approaches remain to be established. (RCH[49], p.7)*

> *However, while practices in relation to diagnosis, technology, surgical techniques, patient information and disclosure have improved significantly, decision-making about healthcare remains challenging.(Victoria Health Department[28])*

There is history of statements that surgical methods have improved. In a 2004 paper "*Genital sensation after feminizing genitoplasty*", Crouch, Minto, Liao, Woodhouse and Creighton state:

> *It is often argued that the results of genital surgery carried out 15 or 20 years ago should be interpreted cautiously. The recent consensus statement on the management of 21-hydroxylase deficiency states there is reason for optimism that future outcomes will be better with current surgical techniques [9]. Although five of the six patients had initial surgery 15 years earlier, one (no. 6) had initial surgery only a year before the study and yet showed markedly abnormal results in temperature and vibration sensation in the clitoris. We are unaware of any data which show that the outcome is improved with modern techniques.*[50]

We also hear claims that outcomes from early surgeries are better than outcomes from adolescent surgeries; it our belief that such assessments are made in part from an inability in early surgeries to determine pre-surgical and post-surgical differences in sexual function and sensation.

Oral testimony to the San Francisco inquiry by Thea Hillman, a woman with CAH, states:

> *[Hospital] response protocol should differentiate between "medically necessary" and "cosmetic." Simply arguing that the surgeries are better now is beside the point because the surgeries are medically unnecessary.*[51]

The implication that there are psychosocial risks associated with 'looking different' and that these are greater than the risks associated with surgical outcomes; appears to be presumed without evidential support. Advocates for Informed Choice (AIC), in a statement to the US National Institutes of Health on 27 June 2013 state that significant gaps in intersex health data include psychological support for parents, families, and intersex children, youth and adults, and also:

> *Health outcomes research looking at children with atypical genitals who did not have early genital surgery. We are unaware of any study in the last 50 years that specifically looks at intersex people who did not undergo early genital surgery.*[52]

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[49] 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.
[50] N.S. Crouch, C.L. Minto, L.-M. Liao, C.R.J. Woodhouse and S.M. Creighton (2004) *Genital sensation after feminizing genitoplasty for congenital adrenal hyperplasia: a pilot study*, in *British Journal of Urology International* 93, 135–138 doi:10.1046/j.1464-410X.2004.04572.x, http://www.ncbi.nlm.nih.gov/pubmed/14678385, accessed 18 November 2012
[51] City and County of San Francisco (28 April 2005) *A Human Rights Investigation into the Medical "Normalization" of Intersex People*. A copy of this document was submitted to the Senate Committee inquiry.
[52] Advocates for Informed Choice, 27 June 2013, *The National Institutes of Health (NIH) Invites Intersex to the Table!* http://aiclegal.org/the-national-institutes-of-health-nih-invites-intersex-to-the-table/ accessed 29 June 2013.

We concur. Neither OII Australia, nor other intersex community or advocacy organisations that we have spoken with (such as the US Advocates for Informed Choice), are aware of any follow up studies on people who have avoided surgery as a primary or comparison group.

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*[38]

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.*[24]

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 properly assess this, or provide support to affected people. APEG is, by definition, a paediatric group, and the RCH DSD submission largely appears similarly focused. The implication is that intersex health issues only affect minors, however this is not the case. Gerard Conway of University College Hospitals, UK comments on the implications of a lack of data on the treatment of *adult* intersex people in a paper to the clinician conference "4th I-DSD Symposium", in June 2013:

> *Care of adults with DSD poses many challenges not least because most information in the field is based entirely based on paediatric experience. There is little guidance for making an accurate diagnosis in adults with a female phenotype who might present with amenorrhoea bypassing paediatric services or who have had a previous diagnostic workup that cannot be verified. Furthermore, the group of women often over that age of 25 for whom paediatric care might not have been transparent in terms of accurate diagnostic information, may have a legacy [of] psychological issues that hinder engagement with medical services.*
>
> *In the surgical field, adults with DSD have to cope with variable outcomes from genital surgery that require ongoing care. Medical aspects of an adult DSD service include optimisation and an individual approach to sex steroid replacement as well as long-term health surveillance such as monitoring bone density and cardiovascular risk.*
>
> *In a world where individuals attending an adult DSD service are often highly informed experts in the field, the role of medical care is often to guide on safety aspects and accept that the evidence base from which conventional practice has developed is questionable. One example of this area is the practice of gonadectomy for women with complete androgen insensitivity syndrome for whom there is very little data in adults*[53]

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:

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[53] Gerard Conway (2013) Paper presented to clinician conference I-DSD, *I-18 The practical management of an adult at risk of gonadal tumourigenesis*, http://www.gla.ac.uk/media/media_279274_en.pdf, accessed 1 July 2013.

> *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.*[54]

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.*[54]

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).*[54]

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.*[54]

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:

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[54] 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.

- *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.*[30]

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:

> *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.*[38]

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.*[45]
>
> *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*[45]

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.*[45]

The treatment of intersex infants in Malaysia and in 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 double standards.

We believe that a principle of non-discrimination should 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.

11. The mental health impact

We invite consideration of the implications for mental health:

- when up to 88% of pregnancies with an intersex variation are terminated.
- when you realise that your body had to be surgically modified to be socially acceptable?
- when you're subjected to reparative therapy, in infancy?
- when parents are told to keep it quiet, and tell no-one.
- when the limited data on long term outcomes of therapy identifies particular concern regarding sexual function and sensation.
- when clinicians change the language used, in a way that disconnects youth from intersex-led support groups.
- when you do disclose that you're intersex, people assume you're trans even when most are not.
- most intersex people are heterosexual and not trans, but you're automatically queered.
- your common issues aren't about your gender, but about responses to your body.

There's 60 years of medical research, but little on mental health outcomes; most focuses on genitalia, or psychosocial development.

Schützmann *et al.* (2009) comments on the lack of accurate data and satisfactory studies on intersex people's health:

> *Evaluation of psychological distress has received relatively little attention in research on persons with disorders of sex development (DSD)… Previous research on psychological distress in persons with DSD is clearly limited by either small sample sizes or lack of standardized measures. Additionally, almost all studies [including Warne et al., Melbourne, 2005] were limited by a selection bias because the samples consisted only of patients who were treated in a certain medical institution with its specific treatment approach.*
>
> *A general limitation of our study is the small sample size. Even though our sample was still rather large compared to other studies on persons with DSD [intersex]…*[55]

All but one of 37 adult participants in Schützmann's pilot study had undergone surgeries, most including gonadectomies (sterilisation), but commonly also clitoris reduction, and also vaginoplasties and mastectomies – when carried out in infancy these have psychosocial rationales. The study found clear evidence of psychological distress:

> *The prevalence rates of self-harming behavior and suicidal tendencies in the sample of persons with DSD were twice as high as in a community based comparison group of non-*

[55] 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.

> *traumatized women, with rates comparable to traumatized women with a history of physical or sexual abuse.*[55]

Within the intersex cohort, the findings were significantly worse for people who had undergone sterilisation:

> *Within the total sample, the subgroup of persons with gonadectomy was significantly more distressed, with depression being particularly increased.*[55]

The sample size was too small to find correlations between psychological distress and other variables, such as specific types of "normalization" surgery.

Australian mental health outcomes

Anecdotally, evidence of poor mental health including suicidal ideation and self-harm is widespread from discussions amongst the membership of OII Australia, typically due to experiences of stigma, medicalisation, and related family issues. However, we have little quantifiable data on mental health outcomes.

Schützmann *et al.* (2009) mentioned a study by Warne *et al.* (Warne was practicing at the Royal Children's Hospital, Melbourne), reported in 2005. The authors say:

> *In the study by Warne et al. (2005), the persons with DSD [intersex] were similarly as distressed as a comparison group of chronic somatically [bodily] ill persons. Even though the rates of psychological distress are not directly comparable to our measures, the results similarly indicate markedly increased distress in persons with DSD. (For comparison, German prevalence rates of significant psychological distress in chronically somatic [bodily] ill persons range from 43% to 50%, see Harter, 2000).*[55]

This provides an example of sampling and selection bias: selecting patients treated only at a particular hospital with a specific approach, and using chronically ill people as a control.

In the study of primary healthcare practitioners by Chris Somers xxy *et al*. there was clear evidence of self harm and suicidal ideation. A social worker interviewee stated:

> *… my understanding is that that the medical profession does not do gender reassignment surgery on young babies anymore because of the adverse affects it has had on adults... adults who have been raised as a particular gender and they could not identify with their gender often ended up with committing suicide or having you know..., very sort of intense mental health problems as a result... my job is to support people given options, and mini choices, like giving information … it's a very difficult decision to make, to support them... ultimately it's the child who should decide what they want to be when they get older.*[37]

Similarly, the case *In the Matter of the Welfare of a child A* (1993) FLC 92-402 (per Mushin J) stated that child A was suicidal.[44] Regrettably, we have no information on the long term outcome for child A.

We note that OII Australia's opposition to early surgical intervention for psychosocial reasons is not based on gender identity issues or changes to sex of rearing, but on the imposition of physical and social stereotypes on infants and children, and the physical and mental impact regardless of gender classification.

Behrmann and Ravitsky recommend that parents receive:

> *information showing the reality of intersex people leading fulfilled lives, as well as the existence of clinical and social biases against diversity in sex, gender and sexual orientation that may influence decisions about the future well-being of their offspring.*[19]

Recommended citation: Morgan Carpenter (1 July 2014) Submission on intentional self-harm and suicidal behaviour in children, Sydney, Organisation Intersex International Australia. http://oii.org.au/27477/submission-intentional-self-harm/