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For intersex human rights, information, and peer support

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Supplementary submission on the Involuntary or Coerced Sterilisation of People with Disabilities in Australia

8 March 2013

1. What is intersex?

Intersex is a term which relates to a range of natural biological traits or variations that lie between “male” and “female”. An intersex person may have the biological attributes of both sexes or lack some of the biological attributes considered necessary to be defined as one or the other sex. Intersex is always congenital and can originate from genetic, chromosomal or hormonal variations.

2. 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 institution. It is funded entirely out of the voluntary contributions of its members. OII Australia employs no staff and receives no public funding. OII Australia is the Australian affiliate of a global network of intersex organisations.

3. About this supplementary submission

This is a supplementary submission in respect of an investigation into the involuntary or coerced sterilisation of people with disabilities in Australia by the Senate Standing Committee on Community Affairs. It is occasioned by three developments since our original submission, dated 15 February, was received by the Committee:

- The Senate’s Legal and Constitutional Affairs Legislation Committee report on the Exposure Draft of the Human Rights and Anti-Discrimination Bill, on 21 February¹.
- The submission to the senate inquiry by the Hon. Diana Bryant AO, Chief Justice of the Family Court of Australia, dated 22 February².
- The publication on 27 February of a framework document by Victoria Health Department entitled “Decision-making principles for the care of infants, children and adolescents with intersex conditions”³.

¹ Report of the Senate Inquiry on the Human Rights and Anti-Discrimination Bill, http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=legcon_ctte/anti_discrimination_2012/report/index.htm, accessed 21 February 2013.

² The Hon. Diana Bryant AO, Chief Justice of the Family Court of Australia, submission #36 on the senate inquiry on involuntary sterilization of people with disabilities, via http://aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/involuntary_sterilisation/submissions.htm, accessed 25 February 2013.

³ Victoria Health Department, February 2013, *Decision-making principles for the care of infants,*

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The developments are unrelated, but individually and together highlight issues of great relevance to the inquiry and to our initial submission. This paper does not replace our first submission, but accompanies it.

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5. Senate report on the Human Rights and Anti-Discrimination Bill

We warmly welcome the recognition by the Senate inquiry that intersex is a biological characteristic, and that “it is unhelpful” for us to receive protection only if we identify as male or female:

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.¹

This acceptance that intersex people should not be required to identify as male or female has yet to impact on policy or practice elsewhere, as will be seen below.

6. The Victorian framework document

The Victorian Government published the framework document on 27 February 2013 following extensive discussion with clinicians and community organisations. The document is described as:

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.

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*a resource for Victorian hospitals responsible for the healthcare of infants, children and adolescents with intersex conditions... The resource synthesises the advice of the Victorian Government, medical, human rights, ethical and legal experts, and community advocates, and outlines best-practice principles to be applied to decision making. It is intended to assist decision makers to safeguard the best interests of patients.*³

The contribution of community advocates, including OII Australia, is evident throughout the document which, immediately on publication, represents best practice in Australia.

Defining intersex, and “disorders of sex development” (“DSD”)

In relation to a definition of intersex, the document states:

Sex is determined by a number of biological factors, including physical attributes, chromosomes, genitals, gonads and hormones. In this resource, the term ‘intersex conditions’ refers to any set of physical or biological conditions that mean a person cannot be said to be exclusively male or female.

*Two of the more common conditions are congenital adrenal hyperplasia and androgen insensitivity syndrome, both of which can result in ambiguous genitalia detectable from birth. Some intersex conditions are not detected until later in life, for example, when a child does not progress through puberty in the usual manner. In addition, some intersex conditions are difficult to classify and can be misdiagnosed as non-intersex conditions (for example, some complex hypospadias).*³

The document’s discussion on the terminology employed in the document is relevant later in this submission. It states:

*There is considerable debate about the appropriate terminology to use to describe intersex conditions. The Australian Human Rights Commission in its 2009 paper, *Surgery on Intersex Infants and Human Rights*, uses the term ‘intersex’ to describe people who are not born, or do not develop, as exclusively male or female. Most Victorian advocates for people with intersex conditions endorse the continued use of the term ‘intersex’.*

Intersex was also endorsed as the preferred terminology by an expert advisory group of Victorian clinicians, with input from intersex community representatives, convened during the initial stages of development of this resource (Victorian Department of Human Services 2009). However, it is important to note that while individuals with intersex conditions may identify as intersex, not all do, nor might a person consider their condition to be an intersex condition, or indeed a ‘condition’ at all.

*Since the publication of the *Consensus Statement on Management of Intersex Conditions* (Lee et al. 2006) there has been a growing international consensus within the clinical community to refer to intersex conditions as ‘disorders of sex development’ or DSDs. In response to this term, a number of Australian and international intersex advocates and academics have voiced their opinion that intersex conditions should not be described as ‘disorders’ or ‘conditions’ because they are part of human variation due to genetic, chromosomal or hormonal factors.*³

We welcome the endorsement of “intersex” by an expert advisory group of Victorian clinicians. We added our voice to that of other Victorian, Australian and international community members and advocates who endorse the term intersex.

Further, while we recognise that some intersex diagnoses require medical attention, we agree that describing an entire range of natural human variation as “disorders” or “conditions” is inappropriate.

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The report is particularly welcome in its acknowledgment that surgical or other medical treatment is not mandatory:

*It is important to note, and to emphasise to patients and their parent/s, that assigning a gender label **does not necessitate undertaking treatment such as surgery or other medical treatment**. Although initial uncertainty can be distressing for parents, it is important in cases where ambiguity exists that experts carefully evaluate the newborn's condition before assigning a gender. The decision is one that will have life-long consequences for the patient and, therefore, should not be made before consideration of all the available evidence.*

Assigning a gender label of male or female to a child, rather than no gender label, does not mean that the label is immutable or that the patient will necessarily identify with that label in future.³

The Victorian framework document alludes to previous policy failings in only a very limited manner, thus:

In the past, some parents have been asked to give consent to treatments where they felt they did not have sufficient information, or where other options (including no treatment or delayed treatment options) were not explained or explored. Further, informed consent requires awareness of potential negative, as well as positive, outcomes.

Consultation

The report was published without public consultation, and with limited private opportunities for intersex organisations to participate. While we obviously are grateful for the opportunity to participate on that level, we believe that there should be an on-going and collaborative consultation process.

References to collaborative approaches within the framework are conflicted, and intersex people are not seen as experts in the treatment of intersex children. On the one hand, community participation is sought to fulfil the following steps:

Principles for supporting patients and parents

In order to achieve international best practice, Victorian hospitals should aim to provide patients and parents with:

- *...standardised, age-appropriate resources for parents, children and adolescents that provide education about sex and gender diversity*
- *information about, and referral to, support groups for both parents/families, and the patient...*

Seeking advice

- *support groups should be involved in dialogue and collaboration as partners in order to achieve international best practice in Victoria.*

In addition, support groups have a particularly important role in providing information to patients and parents during the decision-making phase and beyond. The consensus statement encourages dialogue and collaboration between healthcare professionals and support groups, as partners in delivery of care to patients and their families.

On the other, such on-going consultation is seen as largely optional, medicalised, and limited in scope:

In addition, hospitals are encouraged to create formal opportunities for dialogue and collaboration between healthcare professionals and support groups as partners (Victorian Department of Health 2011). For example, formal opportunities could be arranged for support group members to share their lived experience of having an intersex condition, or having a child with an intersex condition, with members of clinical or ethics teams.

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We believe that community organisations should formally participate, not least in independent evaluation of the ethical and human rights framework for treatment protocols. The intersex community sector must be resourced to permit effective collaboration and the provision of expertise from lived experience.

Psychosocial rationales for surgery

Psychosocial therapeutic rationales for "early reconstruction" (that is, cosmetic surgeries on the genitals of infants) were described in the foundational 2006 *Summary of Consensus Statement on Intersex Disorders and Their Management*, published in *Pediatrics* journal by the American Academy of Pediatrics as including the following:

"minimizing family concern and distress"

"mitigating the risks of stigmatization and gender-identity confusion".⁴

The new Victorian framework document elaborates these as follows:

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

The framework raises concerns about the use of psychosocial rationales:

In particular, the risk of embarrassment about genital appearance and related stigma should not be given undue weight in the decision-making process at the expense of other human rights, ethical and legal principles. For example, using such psychosocial risk factors to justify the urgency of major and irreversible procedures in children who cannot consent, creates a risk to the ethical principle of leaving options open for the child's future autonomy and self-determination...

Most of the international debate about the healthcare of intersex conditions has been concerned with the ethics of performing genital surgery on infants and children. Generally, the focus of concern is not on medically necessary treatment done to avoid physical harm that is proportionate to the level of physical risk that the condition poses to the patient (for example, ensuring a functioning urinary system). The focus of concern is in cases where treatments for cosmetic effect are carried out for conditions that pose little or no physical risk to the patient (for example, to 'normalise' the person's body to make it look more typically male or female).

Treatments where the medical imperative for intervention is not obvious include those performed to protect against potential psychosocial stress associated with 'looking different' and being known by others to look different. Some advocates for intersex people now firmly argue that protection against potential psychosocial stress associated with looking different alone should no longer provide a satisfactory rationale for surgical intervention, and no longer provide a basis for characterising a treatment as therapeutic.

⁴ 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.

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Instead, the focus of treatment should be on functional outcomes appropriate for the child's age (Swiss National Commission of Bioethics, 2012).

We believe that the penultimate sentence in this quotation is directly based on material provided by OII Australia, and we welcome the acknowledgement of our concern. However, we remain concerned that this reports the debate, rather than effects any policy change in a practical sense.

Our perspective about the nature of psychosocial rationales for surgery is balanced against other concerns, and standard protocols for specific intersex diagnoses may not change as a result:

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.

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".

We reject the notion that there are a group of intersex people whose future gender identity is more certain in infancy/childhood, and reiterate that the same risk of harm associated with assigning the wrong sex is present.

Psychological distress

We believe that protocols should focus first and foremost on education and counselling, including family and patient counselling. Patients, in particular, need realistic, accurate information on the trade-offs involved in a treatment decision, but they also need help in developing strategies for dealing with being different. Intersex people remain different even after surgical intervention, as articulated in a major 2012 report on intersex by the Swiss National Advisory Commission on Biomedical Ethics:

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.⁵

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.*

⁵ 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.

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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]...⁶

In relation to the Warne *et al.* study (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).⁶

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-traumatized women, with rates comparable to traumatized women with a history of physical or sexual abuse.⁶

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.⁶

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

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. 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.

‘Looking different’ is a human characteristic, and different ethnic appearances are often associated with discrimination and poor health outcomes. We don't require people to modify their appearance as a result; we try to tackle the discrimination.

The limited role of the Family Court

The Victorian framework document notes that “therapeutic” treatment does not require the consent of the courts, despite the emphasis below:

*However, **certain medical and surgical treatments are sufficiently serious according to law that a parent may not consent.** In those circumstances, parents and medical practitioners must seek court authorisation to proceed with the proposed treatment.*

⁶ 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.

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Court authorisation is required for decisions made on behalf of infants, children and adolescents with intersex conditions, who cannot give consent if all of the following four threshold questions apply to a particular treatment, being that:

- *the proposed treatment is non-therapeutic; and*
- *the proposed treatment is invasive, irreversible and considered ‘major’ treatment; and*
- *there is a significant risk of making the wrong decision about the best interests of the child; and*
- *the consequences of a wrong decision are particularly grave.*³

This means that surgical interventions that are described as therapeutic, including gonadectomies (removal of gonads; sterilisation), and cosmetic treatments that are in accord with an established treatment protocol, do not need court consent. In such cases, including all cases where 3 of the 4 threshold questions apply, “*Parents are able to provide consent*”.

7. The case of Congenital Adrenal Hyperplasia (CAH)

Congenital Adrenal Hyperplasia (CAH) is one intersex variation where “the risk of making a wrong decision about such surgery would be [considered] less significant” or less grave. Murphy, Allen and Jamieson (2011) state:

*CAH does not always result in ambiguous genitalia, but it is the most common cause of genital ambiguity in 46,XX patients. CAH is a term used to represent a group of autosomal recessive disorders that result in impaired steroidogenesis, which can be subdivided into virilizing, and non-virilizing forms... Currently, several mutations in the steroidogenic pathways are known to cause genital ambiguity, although some are much more common than others, and while most will over-virilize a female (46,XX DSD), others will prevent a male fetus from virilizing fully (see 46,XY DSD).*⁷

‘46,XX’ indicates the chromosome count and sex chromosomes commonly associated with women; men typically have 46,XY chromosomes. Some intersex people have 46,XX or 46,XY chromosomes, others may have 45,X chromosomes, 47,XXY chromosomes or additional or mosaic (mixed) chromosomes.

Murphy, Allen and Jamieson (2011) report:

*...most infants with CAH who have ambiguous genitalia are genetically female, reared as female, and have a female post-pubertal gender orientation. The fairly clear-cut potential for fertility in 46,XX CAH plays a large role in the decision to rear as female.*⁷

Similarly, Furtado (2012) reports:

*Gender dysphoria generally affects between 8.5–20% of individuals with DSDs, depending on the type of DSD. Patients with simple virilizing congenital adrenal hyperplasia (CAH), as well as those with CAH and severe virilization, are less likely to have psychosexual disorders than patients with other types of DSD. Early surgery seems to be a safe option for most of these patients.*⁸

Thus, in the context of the Victorian framework document, “*there is more certainty about future gender identity*” in cases of CAH, and early surgery is regarded as “therapeutic”.

⁷ Carla Murphy, L. Allen, Mary Jane Jamieson, 2011, *Ambiguous Genitalia in the Newborn: An Overview and Teaching Tool*, Journal of Pediatric and Adolescent Gynecology, North American Society for Pediatric and Adolescent Gynecology, doi:10.1016/j.jpag.2011.02.004, <http://www.ncbi.nlm.nih.gov/pubmed/21872773> accessed 16 November 2012.

⁸ 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.

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8. The UN Special Rapporteur on Torture

We briefly revisit the report of the UN Special Rapporteur on Torture and a statement of crucial importance to this inquiry:

4. Lesbian, gay, bisexual, transgender and intersex persons

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 anal examinations for the prosecution of suspected homosexual activities, and invasive virginity examinations conducted by health-care providers, 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). The Committee on the Elimination of Discrimination against Women expressed concern about lesbian, bisexual, transgender and intersex women as "victims of abuses and mistreatment by health service providers" (A/HRC/19/41, para. 56).*

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.*⁹

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.*⁹

Psychosocial rationales are focused on the mitigation of stigma and discrimination, but we believe that they unfairly place the burden on the intersex infant to adapt. They also enable parents to provide consent on behalf of patients.

We note the use of language ("intersex"), and the statement regarding "*structural inequalities such as the power imbalance between doctors and patients*".

9. The submission by the Hon. Diana Bryant, AO

In dramatic contrast to the language used by the Victorian health department, the Senate report on the Human Rights and Anti-Discrimination Bill, and that of the UN Special Rapporteur on Torture, the Chief Justice states in her submission to this inquiry:

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"...

While the Victorian health department document displays evidence of community participation, including in the use of its language, the Chief Justice of the Family Court utilises a misquoted medical term and repeatedly encloses the term "intersex" within quotation marks, implying that it has no legal, community or other standing. We find this

⁹ 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.

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illuminating: it shows a lack of consideration of input from the intersex community in the Family Court decision making processes that affect intersex children. Indeed, we are entirely absent from that process. There is a structural inequality resulting in a partisan, disparaging use of language, and no critical evaluation of the validity or efficacy of medical protocols.

The Chief Justice goes on to state:

“Intersex people”

I note the extension of the Committee’s terms of reference to include “intersex people” and bring to the Committee’s attention three Family Court decisions concerning applications for permission to perform surgery on young people born with disorders of sexual [sic] development. They are, in date order:

In the Matter of the Welfare of a child A (1993) FLC 92-402 (per Mushin J)

Re: Lesley [2008] FamCA 1226 (per Barry J)

Re: Sally (supra) (per Murphy J)²

The framework within which the Chief Justice operates is expressed in the following assumption:

I appreciate that the Committee may be contemplating scenarios whereby permission is sought to perform surgery on a young child to give them the appearance of one sex or another...

In relation to this, we note here the recognition in the report of the Senate Inquiry on the Exposure Draft Human Rights and Anti-Discrimination Bill that,

the current requirement in the Draft [Human Rights and Anti-Discrimination] 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.¹⁰

In the Matter of the Welfare of a child A (1993) FLC 92-402

We look in detail at the first case selected by the Chief Justice for mention in her February 2013 submission to the senate inquiry, *In the Matter of the Welfare of a child A (1993) FLC 92-402 (per Mushin J)¹¹*.

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

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¹¹ 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.

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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.*

To summarise the situation:

- The case describes an individual aged 14¾ who was treated since infancy under the standard “therapeutic” protocol for their 46,XX CAH diagnosis.
- The “psychosocial” therapeutic rationale for treatment involved a clitorrectomy/removal of phallus, and irreversible genitoplasty during infancy, to give a “feminine appearance”.
- In other 46,XX children this would commonly be described as “female genital mutilation”.
- The case was brought before the court to provide for surgeries to enable the child to live as male, i.e. the original sex-of-rearing assignment, and the postnatal surgery “*to make them feminine in appearance*” were inappropriate.
- Reassignment was given to require sterilisation through oophorectomy, even though there’s no evidence that this was necessary to enable male sex of living.
- The child was suicidal.
- 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 (why also “*particularly the mother*”?) in an assertion that they had “failed” to properly suppress androgen production through postnatal medication, as if this might have an impact. 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.
- 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.

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As the infant genital surgery described is considered “therapeutic”, it does not ever need to go before the Family Court; this case demonstrates the subjective nature of an assessment that the “*wrong decision about such surgery would be less significant*”. It is of lifetime significance to Child A.

In fact, Child A’s circumstances are not unusual. While it remains the standard protocol for 46,XX CAH children to undergo the same “therapeutic” treatment, 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 “[*early surgery seems to be a safe option for most*]” patients with CAH – even while acknowledging that one in ten cases with that diagnosis have been shown to change gender assignment.

The 2006 Consensus Statement reaches similar conclusions on surgical intervention, despite recognition that patients later undergo gender changes at rates as high as 40% with some intersex diagnoses.

The therapeutic treatment applied in infancy this case, endorsed by the Chief Justice, is by no means universally held and has been criticised in evidence leading to the decision of the UN Special Rapporteur on Torture.

Furthermore, if 46,XX CAH children are to be regarded uncritically as girls, then why does legislation prohibiting female genital mutilation not apply? The Swiss National Advisory Commission on Biomedical Ethics published a globally significant document on intersex in November 2012¹² 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.

It is our view that this case demonstrates the failure of the Family Court and the government 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 independent parties, 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.

Section 9 of our initial submission to the Senate Inquiry deals with surgical outcomes in more details.

Two final, crucial, points:

¹² 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.

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- The standard therapeutic protocol for 46,XX CAH infants, including clitorrectomy and other “psychosocial rationales” remains unchanged everywhere in Australia outside Victoria.
- The therapeutic protocol appears unchanged under the new Victorian framework, in practice. This is because, as described by Murphy *et al*, the standard protocol is widely considered one where there is “*more certainty about future gender identity*” and the psychosocial rationale for genital surgeries remains.

Re: Lesley (Special Medical Procedure) [2008] FamCA 1226

This case saw a request for confirmation of sterilisation associated with a changed sex of rearing in a 4-year old, and the same approach to the sterilisation of a child likely expected to live as a member of a different sex is evident. The judge in this case reports at length on affidavits supplied by the pediatric surgeons and endocrinologists involved in the case, including:

25. Dr Y referred Lesley to Dr Z and his first examination was in March 2006, the child would have been two years of age at that time. He says:

"The diagnosis for [Lesley] was still evolving. I was seeking an understanding of gender identity for [Lesley] given the emerging diagnosis of 17-β/HSD deficiency. In some children with this order there is testosterone present in childhood and in such a case it would be possible to rear the child as a male and allow later virilisation to occur. However, in [Lesley's] case her presentation demonstrates she has a complete block in the expression of testosterone within the testes and this reinforces as correct the initial decision to rear [Lesley] as a girl."

26. Under the heading "Genetic Testing and Confirmation of Diagnosis" at paragraph 15 the doctor opines:

"The 17-β/HSD gene regulates the production of testosterone. The mutation of the gene causes defective production of testosterone, particularly in utero. This is why [Lesley] was born with a vagina and labia and physical appearance of a female."

27. Paragraphs 17 and 18:

"This [future pubertal] process will be effective to produce enough testosterone to cause the virilisation resulting in the development of very severe acne, voice changes, cliteromegaly, excessive facial hair and body hair and a masculine body habitus."

28. It is not known when those changes would occur is a factor which weighs heavily in favour of making an early determination in this matter. The likelihood is she will identify as a female for the future...

29. Paragraph 18:

"Additionally, because the gonads in [Lesley] are in the wrong place there is an increased risk that cancer will develop. This risk is caused by the testes being in a different temperature environment."

*Counsel has informed me that the risk is as high as 28 per cent, which is a further important factor to be taken into consideration.*¹³

The risk factor quoted appears to be maximised, the top end of a range, in order to justify an assertion that gonads should be removed in the short term. The Chief Justice notes in her submission that:

¹³ Family Court of Australia, 2008, *Re Lesley (Special Medical Procedure) [2008] FamCA 1226* (12 December 2008), <http://www.austlii.edu.au/au/cases/cth/FamCA/2008/1226.html>, accessed 1 March 2013.

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In all three cases, a by-product of the surgery was to render the child infertile (although in Re: Lesley the trial judge found that the child was already incapable of having children).²

Anne Tamar-Mattis reports that rationales for sterilisation are often based on weak evidence, and the fertility of intersex people is not valued in the same way that the fertility of other people is valued:

Indeed, some providers may not think of the procedures they are performing as sterilizations when the child's capacity for fertility does not match the gender assignment. For example, if the child is assigned female, especially if she is older and seems content with that assignment, it may not occur to her doctor or her parents that she would have any use for testes. However, if she has testes that could produce viable sperm (or might gain that capacity through future medical advances), this may be her only route to biological parenthood. In such a situation, there may be difficult choices to make at puberty involving weighing the risk of cancer and certainty of developing facial hair and other masculinized features against the potential for fertility. However, making these choices prematurely limits the child's exercise of reproductive freedom as surely as if the child had a more "typical" body.¹⁴

Indeed, in the public hearing on Tuesday 11 December, the Senate Inquiry heard from Professor Glover of the Melbourne Royal Children's Hospital, that the gonads of intersex people are either "non-functioning" or "carry a significant malignancy risk", a lose-lose scenario:

*Prof. Grover: ... Returning to intersex or what are otherwise known as disorders of sex development, gonads are removed but those gonads are non-functioning gonads or carry a significant malignancy risk. If we see somebody who is female who has non-functioning gonads—no hormone producing capacity, no sperm capacity, no egg capacity—but who carries a 30 per cent risk of malignancy, we think those structures are better out than in.
Senator MOORE: That would clearly be therapeutic.
Prof. Grover: Yes, that would be therapeutic. But unfortunately the definition, the issue of what is therapeutic and non-therapeutic—
Senator MOORE: Is critical.¹⁵*

Again, this posits the malignancy of gonads at the top end of a range to justify an assertion with broad impact. We draw attention to our first submission and remarks by Dr Naomi Couch of University College Hospital, London to the UK AIS Support Group, stating that gonadectomies, if required, are carried out at age 18 – post-puberty and with informed patient consent.

The impact of future likely developments in fertility treatments was not assessed. Management of "psychosocial" rationales for sterilisation such as "severe acne, voice changes, cliteromegaly, excessive facial hair and body hair", would not prompt the sterilisation of a non-intersex child, and so we believe that it is discriminatory. Only a "likelihood" of the 4-year old's future gender identity has been established.

¹⁴ A Tamar-Mattis, 2012, *Sterilization and minors with intersex conditions in California law*, in *California Law Review Circuit* 2012, 3:126-135. <http://www.californialawreview.org/articles/sterilization-and-minors-with-intersex-conditions-in-california-law>, accessed 2 March 2013.

¹⁵ Australian Parliament, 2012, Official Committee Hansard, Senate Community Affairs References Committee, Involuntary or coerced sterilization of people with disabilities in Australia, public hearing in Melbourne on 11 December 2012. http://parlinfo.aph.gov.au/parlInfo/download/committees/commsen/cfa53789-4bad-4cd7-a9a2-9f90afe94827/toc_pdf/Community%20Affairs%20References%20Committee_2012_12_11_1601_Official.pdf;fileType=application%2Fpdf#search=%22committees/commsen/cfa53789-4bad-4cd7-a9a2-9f90afe94827/0000%22, accessed 5 March 2013.

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Alternative treatments are available, such as puberty blockers, that would allow the child to decide their own path in their own time.

As with *In the Matter of the Welfare of a child A* (1993) FLC 92-402 (per Mushin J), there are no independent views sought, and no community or patient representation. Consultations were as follows:

41. I take into account the fact that three specialist doctors from different fields are all expressing a recommendation for the procedure to be performed. The institution which brings the application is a highly respected hospital in Australia and internationally. The views expressed have been corroborated by reports from genetic testing laboratories in the United States and France.

42. I note that the [Queensland] Department [of Child Safety] has had the opportunity to be heard the Department has not made any submissions against the orders being made in terms of the application...

47. In conclusion I can say that I am comforted that I have reached what accords with the opinion of the three highly qualified specialist doctors, the hospital authorities generally, the hospital's legal representatives, the parents and the representative of the Department.

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The case demonstrates a structural inequality that results in a discriminatory result for the child concerned.

10. Conclusions

The court system

The absence of community resourcing, our absence from Family Court processes, our historic absence from dialogue over treatment protocols all create a situation where medical evidence supplied has been considered uncritically and without any evaluation of alternative medical data or community voices.

The case mentioned by the Chief Justice of the Family Court in her submission to the Senate Inquiry demonstrates the failure of the court system and the government to deal with structural inequalities that impact directly on the lives of intersex people in Australia. We believe that the court system has been deficient and lacks the competencies required. We believe that this structural inequality must be addressed.

We support the establishment of an expert tribunal to adjudicate on such cases in place of the Family Court, but only where the tribunal can effectively include resourced community participation on an equal footing.

The nature of therapeutic treatment

Most cases where we have concern do not progress to the Family Court, but are managed according to standard therapeutic protocols. It is in this area that we have the most significant concerns.

If therapeutic protocols for 46,XX CAH children are to regard them uncritically as girls, then why does legislation prohibiting female genital mutilation not apply? With what degree of “success” or “necessity” does a cosmetic but irreversible surgical treatment become “therapeutic”?

Why is sterilisation considered necessary to live as a different gender to that previously (legally, surgically and hormonally) assigned, especially when the patient is not an adult able to freely express their own preferred identity?

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Why do gonadectomies take place on infants when, as we pointed out in our initial submission, the standard protocol in London is to wait until the patient is 18, post puberty and with informed consent?

Excluding psychosocial rationales for treatment

We believe that the nature of what is regarded as a therapeutic protocol needs to be changed to exclude psychosocial rationales until an intersex person is old enough to be able to consent.

'Looking different' should not be a reason for irreversible genital surgery.

Clitorectomies and related surgeries must no longer be carried out on intersex infants anywhere in Australia; they should be regarded in the same light as clitorectomies on non-intersex infants.

Gonadectomies should be carefully justified, avoided if sex-of-rearing changes, and generally take place once a patient can give fully informed consent.

Counselling, education and consultation

Protocols should focus first and foremost on counselling and education, including family and patient counselling. Protocols must be kept under review, with full community participation in the review and appraisal process.

Data

The lack of good data is a common theme in studies on intersex health, including the lack of useful sample sizes, non-standardised measures, lack of control groups, and selection bias in research. We wish for children to continue to receive a male or female assignment with recognition that this is mutable but, independent of this, there is a need for children and adults with an intersex status to be tracked through the health system, and more broadly.

Redress

We believe that the issue of an apology and redress for people who have been through non-consensual and inappropriate surgical and hormonal treatments must be considered.

Resourcing

The intersex community must be resourced to support a more active role in our own health care management, and in policy development.

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