



Organisation Intersex International Australia Limited
For intersex human rights, information, and peer support

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Response to Victorian Health Department framework document, ‘Decision-making principles for the care of infants, children and adolescents with intersex conditions’

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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.

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4. The framework document and evaluation principles

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

*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*¹

The contribution of community advocates, including OII Australia, is evident throughout the document. While we have concerns with several matters in the framework document, we broadly welcome its publication as a significant step forward in the care of intersex children in the state. Immediately on publication, the framework document represents best practice in Australia.

This report evaluates the framework document with reference to the following recommended principles for medical intervention:

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. Necessary medical intervention on minors should preserve the potential for different life paths and identities until the patient is old enough to consent.
4. 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”.
5. The framework for medical intervention should not infantilise intersex.
6. The framework for medical intervention must not pathologise intersex through the use of stigmatising language.

5. 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).

The document discusses language and terminology in some detail, addressing concerns about pathologisation. It states:

¹ Victoria Health Department, February 2013, *Decision-making principles for the care of infants, children and adolescents with intersex conditions*, <http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions>, accessed 27 February 2013.

*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.

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. We hope that the language used in the framework will evolve further over time to fully satisfy our 6th recommended principle on non-stigmatising, non-pathologising language.

The framework document 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.

6. Consultation and collaboration with the community

The document 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. We hope that the framework document will prove to be a living document, evolving over time with continuous review and community participation.

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.

The scope of such advisory groups is disappointing. 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.

We note that community engagement is required to ensure a collaborative approach, but resourcing is necessary to make this work. This issue is not addressed in the framework document.

7. Surgical treatment and mutable sex assignments

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.

This recognition that sex assignments are mutable will require amending the legislation and/or procedures governing Victoria's registry of births.

8. 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".²

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. 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,

² 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.

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. The framework still aims to take account of parents' wishes and also "minimise psychosocial risk":

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.

In addition to consideration of future gender identities, it's helpful that the framework now considers the possibility of non-heterosexual sexual orientations and sexual functioning, as well as heterosexual sexual function:

is recommended that those responsible for developing the management plan engage the advice of an appropriate professional who can bring perspective in relation to future sexual functioning, including on a non-heteronormative basis. Therefore, decisions about an infant's future sexual functioning should be informed by principles of sexual diversity, rather than being limited to addressing heterosexual sexual function only.

However, the implications of this on treatment protocols are not described.

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".

'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. Surgery on infants and children unable to consent should no longer be permitted if it has only a psychosocial rationale.

9. Therapeutic treatment where the consequences are not "grave"

The framework document refers to Marion's Case in defining therapeutic treatment:

In Marion's Case, the court defined a 'therapeutic' treatment as a procedure or treatment that is carried out to treat 'a malfunction of disease', however, this definition is not exhaustive.

It notes that "therapeutic" treatment does not require legal consent:

*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.*

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.*

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 these 4 questions apply, "*Parents are able to provide consent*".

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 ... 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.³

Similarly, Furtado (2012) reports:

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.⁴

The protocol which is applied in this instance is described in the Family Court case *In the Matter of the Welfare of a child A* (1993) FLC 92-402 (per Mushin J)⁵.

5. At the time of A's birth he was diagnosed as suffering from a condition known as congenital adrenal hyperplasia. It is interesting to note that his elder sister, suffers from the same condition. As described to me by the Director of the Department of Endocrinology at the hospital ("the endocrinologist") in his very detailed and helpful report dated 15 April 1993:

The disorder results in the over-production in the adrenal glands of the foetus, of androgens (male sex hormones), and in a female foetus, these androgens cause masculinization of the genitalia. The child showed the most extreme degree of masculinization at birth, with a clitoris exactly like a male penis, and labia so completely fused together that the external appearance was of an empty scrotum.

³ 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.

⁴ 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.

⁵ 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.

No mention is made of the adrenal insufficiency associated with Congenital Adrenal Hyperplasia; this issue which typically requires urgent medical attention is not addressed as a matter of any concern. The only issues that are of concern are the infant's physical conformity to gender norms.

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... [in accordance with a male assignment]

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:

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.

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

Child A has undergone a clitorrectomy/phallus removal and feminising vaginoplasty as an infant, and is suicidal owing to the inappropriate nature of surgical and legal sex assignment. The validity of infant “therapeutic” surgical treatment was not questioned by the Family Court; indeed it seems to have been assessed as entirely unremarkable. In other 46,XX children it would commonly be described as “female genital mutilation”.

Reassignment of sex was given to require sterilisation through oophorectomy, even though there's no evidence that this was necessary to enable male sex of living.

The experience of child A is not unusual; 10% of children with 46,XX CAH will go on to identify as male. Furtado⁴ stated that “[e]arly surgery seems to be a safe option for most” patients with 46,XX CAH – “even while acknowledging that one in ten cases have been shown to develop gender dysphoria”⁶.

The 2006 Consensus Statement reaches similar conclusions about surgical intervention for this and other intersex diagnoses even while recognising that patients later undergo gender changes at rates as high as 40% dependent upon the intersex diagnosis.

The “therapeutic” infant surgeries that child A experienced remain unaffected by the implementation of the Victorian framework document.

10. Sterilisation

The case of Androgen Insensitivity Syndrome (“AIS”)

Rationales for sterilisation are not explicitly addressed in the framework document, which permits gonadectomy as a “therapeutic” treatment.

Professor Garry Warne and Doctor Jacqueline Hewitt of the Department of Endocrinology and Diabetes, Royal Children's Hospital, Melbourne, Victoria, in a 2009 paper in the *Medical*

⁶ Advocates for Informed Choice (AIC), 2012, Medical Treatment of People with Intersex Conditions as Torture & CIDF v.2, Testimony to the UN Special Rapporteur on Torture, supplied by AIC.

Journal of Australia demonstrate that gonadectomies remain standard procedure in Australia, on the basis that they are life preserving. Gonadectomies involve the removal of testes and/or ovaries. On gonadectomies, Warne and Hewitt write:

...surgery forms a necessary part of the risk management strategy for preventing gonadal malignancy. In any DSD [“Disorder of Sex Development”] associated with a Y chromosome, there is an increased risk of germ cell cancer, especially when the testes are intra-abdominal (the risk of seminoma in partial androgen insensitivity is 50% for an intra-abdominal testis) or when there is gonadal dysgenesis.⁷

Warne and Hewitt’s assertion regarding the percentage risk of malignancy in internal gonads strongly imply a general, across the board, risk of 50%. This is considerably different from research elsewhere, suggesting either sampling bias, or a hitherto unknown cancer hot spot. It is a generalised statement that has significant adverse consequences: Warne and Hewitt mandate:

- *educating parents and patients about risk;*
- *removing all intra-abdominal gonads that cannot be brought down into the scrotum;⁷*

Evidence from cases brought before the Family Court shows a similar maximising of the potential risk. From *Re: Lesley* (Special Medical Procedure) [2008] FamCA 1226, a case which confirmed sterilization associated with a changed sex of rearing in a 4-year old:

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.⁸

The risk factor quoted appears to be maximised, the top end of a range, in order to justify an assertion that gonads of an infant should be removed in the short term. The protocol described by Warne and Hewitt, which is likely to persist under the framework document, means that the testes of all people with CAIS, and very many with PAIS, are removed in infancy.

Alternative views are numerous, including international expert Katrina Karkazis⁹ or, in the case of AIS specifically, by Quigley et al¹⁰ Batch et al¹¹, Crouch¹². The AISSG UK summarise

⁷ Garry L Warne and Jacqueline K Hewitt, 2009, *Disorders of sex development: current understanding and continuing controversy*, Med J Aust 2009; 190 (11): 612-613.
<https://www.mja.com.au/journal/2009/190/11/disorders-sex-development-current-understanding-and-continuing-controversy>, accessed 23 August 2012.

⁸ 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.

⁹ Katrina Karkazis, 14 November 2008, *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Duke University Press, ISBN 0822343185.

¹⁰ Quigley C.A. et al, 1995, *Androgen Receptor Defects: Historical, Clinical and Molecular Perspectives in Endocrine Reviews*, Vol. 16, No. 3, pp271-321, see AISSG UK, 8 June 2012, "Orchidectomy (Gonadectomy)", http://www.aissg.org/32_gdctomy.htm, accessed 23 August 2012.

¹¹ Batch J.A. et al: *Androgen Insensitivity Syndrome in Reproductive Medicine Review* 1992, 1: 131-150, see AISSG UK, 8 June 2012, *Orchidectomy (Gonadectomy)*, http://www.aissg.org/32_gdctomy.htm, accessed 23 August 2012.

¹² AISSG UK, 8 June 2012, *Orchidectomy (Gonadectomy)*, http://www.aissg.org/32_gdctomy.htm, accessed 23 August 2012.

some of the research in this field, showing sampling bias in many studies, and far lower risks for most intersex people with internal gonads, albeit risks that increase with age:

An early (1963) study (Morris et al) ... estimated a risk of 22% but this is most likely an overestimate, since many of the cases were referred primarily because of the malignancy. A 1992 Danish study reported tumours in 4 of 21 patients but a 1976 study had found no tumours in 23 patients of their own and only 7 tumours in 82 cases gleaned from the literature (8.5%). The risk of such tumours increases with age, the 1976 study (Manuel et al) suggesting an age-related risk of 3.6% at age 25 but approaching 33% at age 50. Two reports from one group (1981 and 1991) estimate the overall risk to be 6 to 9%.¹³

Pleskacova gives a good current (2010) overview, with properly nuanced data, compared to that of Warne and Hewitt, stating:

The most numerous are patients with androgen insensitivity syndrome. The overall prevalence of CIS and invasive type II GCT (seminoma and nonseminoma) in this group is estimated to 5.5%. There is, however, an important difference between patients with complete and partial androgen insensitivity syndrome in whom malignancies occur in 0.8% and 15%.

Looking into higher risk levels amongst a broader set of intersex diagnoses, beyond AIS, Pleskacova found evidence of higher risk:

Patients with gonadal dysgenesis (with either a 46,XY or 45,X/46,XY karyotype) seem to be the most endangered subgroup, although the prevalence in different series is rather incoherent, being reported in 15–100% of all cases [Slowikowska-Hilczer et al., 2001; Cools et al., 2006a]. After the rational interpretation of available data, Cools et al. [2006a] rated the total occurrence at 12% and possibly at more than 30% if gonadectomy had not been performed.¹³

In relation to the lower risks associated with AIS, the Androgen Insensitivity Support Group (AISSG) UK report:

At the 2009 AISSG UK group meeting Dr. Naomi Crouch (gynaecology registrar at the University College Hospital London multi-disciplinary intersex clinic) talked about the cancer/gonadectomy issue, as follows:

Guest speaker Naomi Crouch said that the risk of cancerous changes in CAIS testes is thought to be about 5% by early adulthood and that gonadectomy at age 18 is recommended. The advantage of not doing it in childhood is that the intact testes will facilitate a natural puberty (testosterone from the testes gets converted in the body to oestrogen which promotes breast growth etc.).¹²

Note that Crouch gives the recommended age of surgery in the UK as 18, the age of majority, while Warne and Hewitt, in an Australian paper, were referring to the same surgeries in “children too young to consent on their own behalf”. The AISSG UK continue:

A group member asked why then aren't breasts removed from young XX women, when the risk of breast cancer in the general population of women is about 8%? Naomi confirmed that the risk of breast cancer in general is about 1 in 12, but it was easier to monitor breast tissue for changes than it is to monitor intra-abdominal testes in AIS women. Ultrasound technicians, for example, do not have so much expertise in terms of knowing what to look for, since these conditions are rare.¹²

¹³ Pleskacova J. et al, 17 June 2010, *Tumor Risk in Disorders of Sex Development in Sexual Development Sex Dev*, DOI: 10.1159/000314536, <http://www.aissg.org/PDFs/Pleskacova-et-al-Tumour-Risk-2010.pdf>, accessed 23 August 2012.

Such surgeries in Australia take place before the age of majority, while a child is not able to consent, while good practice in the UK is that surgery takes place at age 18.

In failing to address issues with therapeutic protocols, this report fails to meet the 1st, 3rd and 4th principles, ensuring that medical intervention does not presume normalization as a goal, preserving the potential for different life paths, and deferring intervention until a patient is able to consent in person.

Re: Lesley [2008]

The Chief Justice notes in a submission to the Senate Inquiry on involuntary sterilization of people with disabilities that:

In all three cases, a by-product of the surgery was to render the child infertile (although in Re: Lesley [2008] the trial judge found that the child was already incapable of having children)¹⁴.

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

...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.¹⁵

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.¹⁶

¹⁴ 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.

¹⁵ 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.

¹⁶ 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.

As with earlier examples relating to AIS, this posits the malignancy of gonads at the top end of a range to justify an assertion with broad impact.

In the case of Re: Lesley [2008], impact of future likely developments in fertility treatments was not assessed. Management of “psychosocial” rationales for sterilisation such as “severe acne, voice changes, cliteromegaly [large clitoris], 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 was established.

The treatment regarded as therapeutic fails to facilitate a normal puberty wherever possible, and to permit the patient to personally consent. It is unclear whether or not the application of the Victorian decision making framework would change this.

11. Long term follow-up

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.

*There is a need for representative studies with sufficient numbers of cases and control groups comprising untreated or non-invasively treated ... subjects. Data should also be collected on patient satisfaction and on the effectiveness of various treatment methods and surgical sex assignment procedures.*¹⁷

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]...*¹⁸

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.

¹⁷ 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.

¹⁸ 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.

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).¹⁸

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.¹⁸

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.¹⁸

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.

Creighton, in another relatively large scale study, remarks on the difference between cosmetic and functional outcomes, and a need for repeat surgery:

it is possible to have a good cosmetic outcome and yet still have a vagina too narrow for sexual intercourse. It is also possible to have a good anatomical outcome, i.e. a normal calibre vagina, and yet still have poor sexual outcome. Vaginal stenosis is the main anatomical problem and is common, occurring in 36–100% after surgery in infancy [7,8]. Even after a 'one-stage' genitoplasty, revision at adolescence is frequently necessary and the family should be prepared for this. Revision surgery may be on the clitoris, with up to 44% undergoing clitoral revision [9], or the vagina, with estimates of up to 80% revision rate...

Two studies assessed in more detail psychosexual function in intersex women after genital surgery. The first compared 34 women with CAH to their sisters without CAH [17]. The CAH group were less likely than their sisters to be sexually active and more likely to have orgasmic dysfunction (33% vs 0%, respectively). The second study of 19 women with CAH compared them to a control group of women with diabetes [18]. Again, those with CAH had significantly less sexual experience, worse orgasmic dysfunction, and were

*more likely to report problems with penetration. They attributed their difficulties to their surgery.*¹⁹

Crouch, Minto, Liao, Woodhouse and Creighton explore the issue of sensitivity further in a 2004 paper “*Genital sensation after feminizing genitoplasty*”:

*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.*²⁰

Köhler, *et al* report that:

*Prenatal deficit of androgens or androgen action results in atypical genitalia in individuals with XY disorders of sex development (XY,DSD). XY,DSD include mainly disorders of gonadal development and testosterone synthesis and action. Previously, most XY,DSD individuals were assigned to the female sex. Constructive genital surgery allowing heterosexual intercourse, gonadectomy, and hormone therapy for feminization were often performed. However, outcome studies are scarce.*²¹

This scarcity of outcome studies is a matter of great concern to OII Australia. Köhler *et al* presented a study of 57 people with XY forms of intersex accessed via a German multi-centre clinical evaluation study, in an attempt to address that deficit in a way that eliminates sample and selection bias. They found:

*Dissatisfaction with function of the surgical result (47.1%) and clitoral arousal (47.4%) was high in XY,DSD partially androgenized females after feminization surgery. Dissatisfaction with overall sex life (37.5%) and sexual anxieties (44.2%) were substantial in all XY,DSD individuals. Problems with desire (70.6%), arousal (52.9%), and dyspareunia [painful intercourse] (56.3%) were significant in XY,DSD complete females. 46,XY partially androgenized females reported significantly more often partners of female (9.1%) or both sexes (18.2%) and dyspareunia (56.5%) compared with controls. Individuals with complete androgen insensitivity syndrome stated significant problems with desire (81.8%), arousal (63.6%), and dyspareunia (70%).*²¹

In summary, the few impact studies that show the long term effects of infant and childhood surgeries show poor results, including repeat surgeries, and a high prevalence of partially- or non- functional, insensate genitalia that deeply affect adult relationships and life satisfaction.

The Victorian framework document does not address data adequacy issues, making reference only to studies carried out within the location-specific and treatment methodology-specific Royal Children’s Hospital, meaning that these studies are subject to selection bias.

¹⁹ Sarah M Creighton, 2004, *Long-term outcome of feminization surgery: the London experience*, in *British Journal of Urology International* 93, SUPPLEMENT 3, 44–46, <http://onlinelibrary.wiley.com/doi/10.1111/j.1464-410X.2004.04708.x/abstract>, accessed 18 November 2012.

²⁰ N.S. Crouch, C.L. Minto, L.-M. Laio, 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

²¹ Birgit Köhler, Eva Kleinemeier, Anke Lux, Olaf Hiort, Annette Grüters, Ute Thyen and the DSD Network Working Group, 16 November 2011, *Satisfaction with Genital Surgery and Sexual Life of Adults with XY Disorders of Sex Development: Results from the German Clinical Evaluation Study*, in *The Journal of Clinical Endocrinology & Metabolism* jc.2011-1441, <http://jcem.endojournals.org/content/early/2011/11/10/jc.2011-1441.abstract>, accessed 22 November 2011.

The framework document does not adequately address principle 2, regarding evidence of long term benefit.

12. Counselling and information provision

Children will not be aware of the differences about their bodies unless they are made to feel different by their parents and carers, including medical practitioners. Supportive family counselling is essential and the Swiss Commission makes an valuable statement regarding the purpose of such support – to facilitate a close bond between parents and child:

The initial aim of counselling and support is therefore to create a protected space for parents and the newborn, so as to facilitate a close bond. In addition, the parents need to be enabled to take the necessary decisions on the child's behalf calmly and after due reflection. In this process, they should not be subjected to time or social pressures. Parents' rapid requests for medical advice or for corrective surgery are often a result of initial feelings of helplessness, which need to be overcome so as to permit carefully considered decision-making.

It is important to bear in mind and also to point out to the parents that a diagnosis does not in itself entail any treatment or other medical measures, but serves initially to provide an overview of the situation and a basis for subsequent decisions, which may also take the form of watchful waiting.

It is our view that protocols should focus first and foremost on counselling and education, including family and patient counselling. The Victorian framework document has clearly been influenced by this approach, proposed by the Swiss ethics commission:

*Intensive support, education and counselling during the decision-making phase
The diagnosis of an infant, child or adolescent with an intersex condition can be a distressing event for patients and parents. There is a need at this time for intensive support to enable patients and parents to make the difficult and life-changing decisions that will ultimately be in their or their child's best interests. The role of those responsible for the care and support of patients and parents is to ensure a robust, transparent and consistent decision-making process, so that patients and parents have access to the best options available...*

The aim of counselling and support during this phase should be to facilitate the formation of a close and loving bond between the parent/s and their child and to create an appropriate environment for reasoned decision making (Swiss National Advisory Commission on Biomedical Ethics 2012). Support, education and counselling should be available even if the patient has been discharged home.

However, the framework also retains an undue emphasis on *intense* family counselling, *quickly* and on *complex* issues, primarily up until the point where a sex assignment is decided – a defined decision-making period:

In the decision-making phase, patients and parents need to quickly understand very complex information in order to make decisions in their or their child's best interests. The provision of clear and informative resources can assist this communication, and it is recommended that hospitals collate or develop standardised, age-appropriate resources for this purpose.

It is very helpful that information provision must include open information, including provision by support groups, and information regarding adult understandings of intersex – but the provision of this information is not resourced:

It is important that these resources include education about sex and gender diversity, that is, different understandings of sex and gender experienced by adults with intersex conditions.

In addition, support groups have a particularly important role in providing information to patients and parents during the decision-making phase and beyond.

The provision of accurate data on long term impact is also extremely desirable, but a threshold for the quality of that data is not established:

Parents should receive comprehensive information on the implications of the proposed medical or surgical interventions, including evidence of the long-term impact and of gaps in the available research.

13. Redress

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

Some patients who are now adults regard the decisions made when they were infants, children or adolescents as not being in their best interests. For example, patients have reported significant negative consequences of decisions where they ultimately feel that the wrong gender was assigned, where irreversible surgery was performed, and where the effects of surgery such as loss of sensation or loss of potential fertility have had lasting consequences for the person's quality of life. In some cases, these outcomes occurred because the risk of embarrassment about difference and the related stigma was given undue weight in the decision-making process...

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.

In contrast, the Swiss biomedical ethics report talks both of previous failures to address the concerns of intersex people, and of criminal sanction against unwanted genital surgeries:

Until just a few years ago, questions concerning social attitudes to – and the medical management of – individuals with ambiguous sexual characteristics were not widely debated. It is largely thanks to the efforts of self-help/ advocacy groups that this situation has changed, and that increasing attention is now being paid to the topic of “intersexuality” in the media and in professional circles – including the fields of medical law and ethics – both nationally and internationally. The Swiss National Advisory Commission on Biomedical Ethics ... welcomes this development and hopes that, by issuing this Opinion, it can help to dispel any remaining taboos surrounding the topic...

The suffering experienced by some people ... as a result of past practice should be acknowledged by society. The medical practice of the time was guided by sociocultural values which, from today's ethical viewpoint, are not compatible with fundamental human rights, specifically respect for physical and psychological integrity and the right to self-determination...

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.

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.

14. Summary

The report fails to fully satisfy our recommended principles:

1. Medical intervention should not assume crisis in our difference, nor normalisation as a goal.
Psychosocial normalisation rationales are still considered therapeutic.
2. Medical, and in particular surgical, interventions must have a clear ethical basis, supported by evidence of long term benefit.
There is no evidence that treatment is supported by long term and/or comparative studies.
Studies suffer from selection bias, being limited to studies of patients treated by the Royal Children's Hospital.
3. Necessary medical intervention on minors should preserve the potential for different life paths and identities until the patient is old enough to consent.
Psychosocial therapeutic interventions are still permitted, notably in cases where, like the child with 46,XX CAH in In the Matter of the Welfare of a child A, where surgery is considered a safe option.
4. 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".
Early intervention is still permitted, notably where there is a subjective assessment that surgery is a safe option.
5. The framework for medical intervention should not infantilise intersex.
The framework recognises that is applicable to infants, children and adults, and there remains a danger that treatment protocols may place insufficient weight on the impact of treatment on the future adult, however, the report does attempt to satisfy this concern.
6. The framework for medical intervention must not pathologise intersex through the use of stigmatising language.
The use of the term 'intersex', notably with clinician support, is strongly welcomed.
The use of the term 'condition' is less welcome, and it is hoped that future versions of the framework will focus more on the intersex person rather than a perceived impairment.

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