



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

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13 September 2015

## **Submission on the Review of Part B of the Ethical Guidelines for the Use of Assisted Reproductive Technology in Clinical Practice and Research, 2007**

### **1. OII Australia**

Organisation Intersex International Australia Limited (OII Australia) is a national body by and for people with intersex variations. We promote the human rights of intersex people in Australia, and provide information, education and peer support. OII Australia is a not-for-profit company, recognised by the Australian Taxation Office as a charitable Public Benevolent Institution.

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

### **2. Our interests in this inquiry**

Our interests in, and responses to, this inquiry focus on issues of:

#### **4. Information giving, counselling and consent**

and the ethics and permissibility of:

#### **8. Preimplantation genetic testing (PGT), including selection for particular characteristics.**

#### **Appendix 3. Sex selection.**

In particular, we focus our attention on the de-selection of intersex traits on the basis that they may be considered to be “serious genetic conditions”. This submission extends our submission of 30 April 2014.

### **3. Preimplantation genetic testing**

The current *Public consultation – 2015* guidelines permit the exercise of clinical judgement in determining what “genetic conditions” may be screened stating in section 8:

*Preimplantation genetic screening (PGS) is used to screen for unspecified and multiple genetic or chromosomal anomalies in embryos from parents who do not have any diagnosed genetic condition...*

*PGT may be used to:*

- *prevent conditions that would seriously harm the person who would be born*
- *select the sex of an embryo to reduce the risk of transmission of a serious genetic condition*
- *improve ART outcomes.*

The guidelines refrain from defining “serious genetic conditions”, stating in section 8.13 that:

- *what might be considered a ‘serious genetic condition’ is controversial and may change over time as new effective treatments become available.*
- *there are differing perceptions of genetic conditions held within the community*
- *the practice of selecting against some conditions may threaten the status of, and equality of opportunity for, people who have that condition*

Intersex variations, including 5 alpha Reductase Deficiency, Androgen Insensitivity Syndrome, Congenital Adrenal Hyperplasia, 45X0 (Turner Syndrome) and 47XXY (Klinefelter syndrome) are examples of such “genetic conditions”. They may be tested through PGT and other means. Evidence from the UK clearly states that such traits are designated as “sufficiently serious” “genetic conditions” that they may be de-selected.<sup>1</sup>

The use of the same language in the NHMRC *Draft Ethical guidelines on the use of assisted reproductive technology in clinical practice and research* thus provides us with significant cause for concern.

Further, it is troubling that the guidelines propose to prohibit selection in favour of such undefined “serious genetic conditions”.

Recognition of controversies over what might be regarded a “serious genetic condition” is welcome, however, the guidelines provide insufficient guidance on this issue.

Guidelines include some assessment of the impact of a genetic variation on the life of the person who would be born, including “degree/spectrum or severity”, however, the guidelines do not acknowledge the role of social stigma in creating concern about the life of the person who would be born.

Rather than a test on the basis of “seriousness of a genetic condition”, the test should require:

- **Major impairment:** demonstration of a “major physical or mental impairment that severely limits quality of life”. Quality of life should be demonstrably impacted through disability or illness to the degree that social function or life expectancy are severely limited.
- **Non-discrimination:** Clinicians are members of society, and subject to the same prejudices and attitudes as other members of society. Rather than simply identifying a consequential impact on equality of opportunity for people with a genetic variation, the practice of PGT must not discriminate other than on the basis of a “major physical or mental impairment that severely limits quality of life”.
- **Elimination of any possibility for conflicts of interest:** the policing of loosely worded guidelines via a suggestion that clinicians consult an ethics committee is inadequate given a history of failures in ethical conduct and a conflict of interest inherent in a situation where a institution stands to financially benefit from the use of PGT.
- **Exclusion list:** Strong consideration should be given to publication of a list of genetic variations considered to be not suitable for PGT.

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<sup>1</sup> Human Fertilisation & Embryology Authority. “PGD Conditions Licensed by the HFEA,” February 21, 2015. <http://guide.hfea.gov.uk/pgd/>

## Stigma and subjectivity

Intersex traits presently remain stigmatised in Australia and most other parts of the world. The United Nations Office of the High Commissioner for Human Rights states:

*Intersex people are born with sex characteristics (including genitals, gonads and chromosome patterns) that do not fit typical binary notions of male or female bodies...*

*Because their bodies are seen as different, intersex children and adults are often stigmatized and subjected to multiple human rights violations, including violations of their rights to health and physical integrity, to be free from torture and ill-treatment, and to equality and non-discrimination.<sup>2</sup>*

The Australian parliament has, via the 2013 Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act,<sup>3</sup> acknowledged stigma attached to an intersex status, and prohibited discrimination in most settings.

The role of stigma in modifying the bodies of people born with intersex variations is widely recognized, including in clinical papers that acknowledge decision-making based on “parental distress” and “social stigma”. Decision making is thus not value-neutral.

The 2013 Community Affairs References Committee report on the *Involuntary or coerced sterilization of intersex people in Australia*<sup>4</sup> recognized intersex people’s right to health, raising concern about involuntary medical treatment and the unnecessary “disordering” of intersex variations:

*2.4 Not everyone who is intersex has a health problem: whether they experience a 'disorder' is not defined by whether they are biologically 'intersex'. A person might have a form of Androgen Insensitivity Syndrome and present as having an uncommon physiology that appears neither completely female nor completely male, and they may or may not experience health issues. As the Swiss National Advisory Commission on Biomedical Ethics put it:*

*not all cases of DSD involve a (pathological) "disorder", i.e. a functional impairment associated with suffering. Not infrequently, a case of DSD may involve a variation from a norm of sex development which does not require medical treatment. From the perspective of those affected, the term "disorder" may thus appear stigmatizing<sup>11</sup>*

The presence of social stigma is an inadequate rationale for genetic selection on the basis of intersex traits. De-selection on grounds of intersex status would, instead, comprise an additional violation of human rights.

## Discrimination

In 2015, the Council of Europe Commissioner for Human Rights has recommended:

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<sup>2</sup> United Nations, and Office of the High Commissioner for Human Rights. “Free & Equal Campaign Fact Sheet: Intersex,” 2015. [https://unfe.org/system/unfe-65-Intersex\\_Factsheet\\_ENGLISH.pdf](https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf)

<sup>3</sup> Australia, Parliament, and ComLaw. *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013*, ComLaw Authoritative Act C2013A00098. Canberra, 2013. <http://www.comlaw.gov.au/Details/C2013A00098/>

<sup>4</sup> Australian Senate, and Community Affairs References Committee. *Involuntary or Coerced Sterilisation of Intersex People in Australia*. Canberra: Community Affairs References Committee, 2013. [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Involuntary\\_Sterilisation/Sec\\_Report/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index)

*National and international medical classifications which pathologise variations in sex characteristics should be reviewed with a view to eliminating obstacles to the effective enjoyment, by intersex persons, of human rights, including the right to the highest attainable standard of health.*<sup>5</sup>

The Council of Europe's Issue Paper on *Human rights and intersex people* comments directly on the use of preimplantation genetic testing to de-select intersex traits (citations omitted):

*Intersex people's right to life can be violated in discriminatory "sex selection" and "preimplantation genetic diagnosis, other forms of testing, and selection for particular characteristics". Such de-selection or selective abortions are incompatible with ethics and human rights standards due to the discrimination perpetrated against intersex people on the basis of their sex characteristics.*

*The Council of Europe Convention on Human Rights and Biomedicine (ETS No. 164) prohibits discrimination on the grounds of a person's "genetic heritage" as well as the use of techniques of medically assisted procreation "for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided". The explanatory report of the convention leaves the definition of "hereditary sex-related disease" open to the "internal law" of member states. Nonetheless, the report raises concern with regard to genetic testing as it "may become a means of selection and discrimination".*

*While the convention has not yet been tested with regard to its applicability to intersex, many Council of Europe institutions have already raised concerns about the use of sex selection techniques. In its 2011 resolution on pre-natal sex selection, PACE stressed that "the social and family pressure placed on women not to pursue their pregnancy because of the sex of the embryo/foetus is to be considered as a form of psychological violence" and that the practice of forced abortions should be criminalised. Similarly, in a recent Human Rights Comment, the Commissioner for Human Rights called for the "deeply discriminatory practice" of sex selection to be "vigorously countered and banned in law". The Committee of Ministers' 2002 recommendation clearly called on member states to "prohibit enforced sterilisation or abortion, contraception imposed by coercion or force, and pre-natal selection by sex, and take all necessary measures to this end".*

## Subjectivity and conflicts of interest

A 2009 Dutch study of 210 physicians examined the dispositions of general practitioners, gynaecologists and plastic surgeons to refer or perform a surgical labia minora reduction.<sup>6</sup> It found that physician attitudes towards women's labia minora varied by specialism, such that:

- *More plastic surgeons regarded the picture with the largest labia minora as distasteful and unnatural, compared with general practitioners and gynecologists.*
- *Irrespective of the woman's labia minora size and the absence of physical complaints, plastic surgeons were significantly more open to performing a labia minora reduction procedure than gynecologists.*

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<sup>5</sup> Council of Europe, and Commissioner for Human Rights. "Human Rights and Intersex People, Issue Paper," April 2015.  
[https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper\(2015\)1&Language=lanEnglish&Ver=original](https://wcd.coe.int/ViewDoc.jsp?Ref=CommDH/IssuePaper(2015)1&Language=lanEnglish&Ver=original)

<sup>6</sup> W Reitsma, MJ Mourits, M Koning, A Pascal, B van der Lei, 2011, *No (wo)man is an island - the influence of physicians' personal predisposition to labia minora appearance on their clinical decision making: a cross-sectional survey*, in *The Journal of Sexual Medicine*, 2011 8(8):2377-2385, doi: 10.1111/j.1743-6109.2011.02321.x, <http://europepmc.org/abstract/MED/21595842>, accessed 21 August 2013.

This highlights the potential for a conflict of interest comparable to the situation presented by clinicians who benefit from the implementation of PGT making an assessment of the ethics and appropriateness of such testing.

Furthermore, the same research found that physicians' gender is a significant influence: "male physicians were more inclined to opt for a surgical reduction procedure than their female colleagues".

2015 revelations regarding a torture program administered by the CIA, along with many other instances of ethical abuses in clinical settings,<sup>7</sup> similarly show how clinicians are as vulnerable to prevailing social attitudes as other members of society.

Subjectivity in defining "serious genetic conditions" is elucidated by Professor Jeff Nisker in his article *Informed Choice and PGD to Prevent "Intersex Conditions"* in the American Journal of Bioethics. He writes:

*I began laboratory research on PGD in 1989 to offer an option to Canadian women already undergoing in vitro fertilization (IVF) who carried a gene for a "severe" genetic condition and planned to undergo amniocentesis. However, when our study moved from "the mouse to the human" in 1993 and the press pounced, many couples with no indication for IVF and no inherited risk called my office requesting PGD. The most frequent genetic condition they desired to prevent was XX (they wanted a boy)...*

*Once a difference becomes a medical disorder to which the medical profession is dedicating time and resources to prevent, procedures to this end become endowed with appropriateness<sup>8</sup>*

He concludes:

*If we accept the use of genetic testing to prevent children whose genitalia are along a continuum of difference, we must accept genetic testing to prevent a child of any physical characteristics not desired by potential parents*

#### 4. Sex and gender selection

The existence of both intersex and transgender populations demonstrates flaws associated with sex selection technologies: inherent assumptions that sex characteristics are unambiguous, and that sex classification predetermines future gender identity.

In an analysis of "psychosocial" reasons to conduct medical interventions on infants and children with intersex variations, the Senate Community Affairs References Committee remarked, in 2013:

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

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<sup>7</sup> Copland, Simon. "CIA Torture Is Only Part of Medical Science's Dark Modern History." *The Guardian*, June 22, 2015. <http://www.theguardian.com/science/blog/2015/jun/22/cia-torture-is-only-part-of-medical-sciences-dark-modern-history>

<sup>8</sup> Jeff Nisker (2013) *Informed Choice and PGD to Prevent "Intersex Conditions"* in the *American Journal of Bioethics*, 13:10, 51-53, <http://dx.doi.org/10.1080/15265161.2013.828119>, accessed 11 September 2013.

*such as intersex. Surgery is unlikely to be an appropriate response to these kinds of issues.*<sup>9</sup>

It seems likely that the same issues are apparent in suggestions that parental bonding or esteem may benefit from medical intervention aimed at procuring a child with specific sex characteristics: it avoids the central issues of stigma, parental acceptance and capacity for bonding.

International evidence shows that one gender, women, is predominantly impacted by sex selection. As with the dubious and contested designation of intersex traits as serious genetic conditions, sex selection reinforces binary gender roles and sexism. It seems to us that genetic screening on the basis of sex and presumed gender identity fail a test of equal opportunity, in particular for people with the condition of having XX chromosomes.

## 5. Information giving, counselling and consent

The available evidence suggests that parental decision making on interventions applicable to foetuses and infants with intersex variations is strongly impacted by the types of information provided, and the disposition of the information provider.

Holmes reports that:

*Dorothy Wertz's research shows that 49% of genetic professionals, and 48% of primary care physicians would favour selective abortion of fetuses with Klinefelter Syndrome. Meanwhile, 42% of genetics professionals and 37% of primary care physicians, favour selective abortion of fetuses with Turner Syndrome... In a separate test for other measures and with other health care providers, only about 12% would focus on the positive aspects for Klinefelter syndrome and only about 16% would do so with Turner syndrome.*<sup>10</sup>

Similarly, Streuli et al, 2013, found that the medicalisation of information strongly impacts on decision making in relation to “normalising” surgeries:<sup>11</sup>

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<sup>9</sup> Australian Senate, and Community Affairs References Committee. *Involuntary or Coerced Sterilisation of Intersex People in Australia*. Canberra: Community Affairs References Committee, 2013.

[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Involuntary\\_Sterilisation/Sec\\_Report/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index)

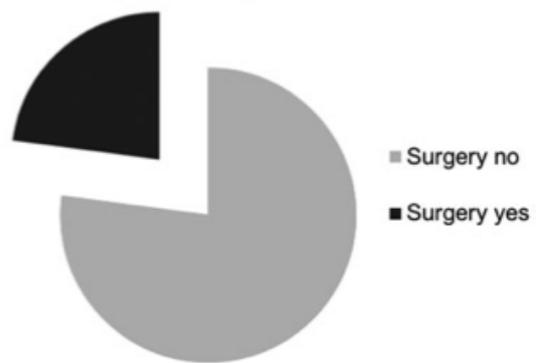
<sup>10</sup> Holmes, M. Morgan. “Mind the Gaps: Intersex and (Re-Productive) Spaces in Disability Studies and Bioethics.” *Journal of Bioethical Inquiry* 5, no. 2–3 (June 2008): 169–81. doi:10.1007/s11673-007-9073-2.

<sup>11</sup> Streuli, Jürg C., Effy Vayena, Yvonne Cavicchia-Balmer, and Johannes Huber. “Shaping Parents: Impact of Contrasting Professional Counseling on Parents’ Decision Making for Children with Disorders of Sex Development: Parent Decision in Disorders of Sex Development.” *The Journal of Sexual Medicine* 10, no. 8 (August 2013): 1953–60. doi:10.1111/jsm.12214.

**Information by medicalizing endocrinologist**



**Information by demedicalizing psychologist**



Persons with intersex variations, including variations that may be de-selected in the UK on the basis that they are “serious” “genetic conditions” are capable of living happy and health lives, and contributing effectively to society.

Medicalised decision making fails to reflect the lived reality of people born with atypical sex characteristics.

Members and friends of OII Australia include persons with 5 alpha reductase deficiency, androgen insensitivity syndrome and congenital adrenal hyperplasia in senior management roles. Most are not public about their intersex traits due to stigma, while others are finding that society is rapidly becoming more accepting.

Amongst those, Tony Briffa JP, who has partial androgen insensitivity syndrome, is a former mayor of Hobsons Bay, Victoria.

Andie Hider, a board member of OII Australia and former president of the Genetic Support Network of Victoria, comments:

*We had a situation where pre-natal testing showed that a foetus had AIS and a genetic counsellor told the parents they should terminate the pregnancy. The mother chatted to her GP about this advice and the GP advised the mother they had a patient with AIS and it might be possible for the mother to meet her if she agreed. The GP then sought permission to meet the mother from the woman with AIS. The mother turned up at a major corporation expecting to meet a secretary or worker, instead she was shown to the office of the CEO. The woman explained AIS had not stopped her from achieving any of the things she wanted and her success spoke for itself. The prospective parents immediately abandoned the idea of termination. When confronted with this the genetic counsellor admitted they had never met anyone with AIS, but because it was listed as a serious genetic condition had advised based on this alone.*

Similarly, we are aware of multiple persons with 47XXY (often diagnosed as Klinefelter syndrome) who have undertaken postgraduate research studies. Chris Somers XXY, for example, a former vice-president of OII Australia, has completed a masters research study on “Intersex and Androgyny and Implications for Provision of Primary Health Care” for the Combined Universities Centre for Rural Health, WA.<sup>12</sup>

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<sup>12</sup> Somers xxy, Chris, Tracy Reibel, and David Whyatt. “Intersex and Androgyny and Implications for Provision of Primary Health Care.” Geraldton, WA: Combined Universities Centre for Rural Health, 2008. <http://www.curch.uwa.edu.au>

As discussed in our 2014 submission, the impact of diagnosis with 47XXY chromosomes far outweighs the risks associated with that variation; diagnostic criteria are themselves skewed by low overall rates of diagnosis.

Decision making in relation to uses of PGT are inadequately informed by the lived experience of people born with intersex traits. Limited awareness of the actual life experience and contribution of people with intersex variations can lead to inadequate assessment of quality of life and overstating the “seriousness” of a genetic variation.

Information giving and counselling must include non-pathologising information, aimed at supporting a philosophy of self acceptance; such a philosophy is a core component for good mental health and can impact positively on parental bonding.

## 6. Recommendations

### Information giving, counselling and consent

Decision making in relation to uses of PGT are inadequately informed by the lived experience of people born with intersex traits. Information giving and counselling must include non-pathologising information, aimed at supporting a philosophy of self acceptance; such a philosophy is a core component for good mental health and can impact positively on parental bonding.

### Preimplantation genetic testing

The existing tests in 8.13 be augmented by new requirements requiring that uses of PGT demonstrate:

- **Major impairment:** demonstration of a “major physical or mental impairment that severely limits quality of life”. Quality of life should be demonstrably impacted through disability or illness to the degree that social function or life expectancy are severely limited.
- **Non-discrimination:** Clinicians are members of society, and subject to the same prejudices and attitudes as other members of society. Rather than simply identifying a consequential impact on equality of opportunity for people with a genetic variation, the practice of PGT must not discriminate other than on the basis of a “major physical or mental impairment that severely limits quality of life”.
- **Elimination of any possibility for conflicts of interest:** the policing of loosely worded guidelines via a suggestion that clinicians consult an ethics committee is inadequate given a history of failures in ethical conduct and a conflict of interest inherent in a situation where a institution stands to financially benefit from the use of PGT.
- **Exclusion list:** Strong consideration should be given to publication of a list of genetic variations considered to be not suitable for PGT.

### Sex selection

The practice of sex selection not be permitted for social, child replacement, or family balancing purposes. Selection on the basis of sex and/or sex characteristics should meet requirements of non-discrimination, major impairment, and conflicts of interest.