



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

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## **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 intersex people. We promote the human rights of intersex people in Australia, and provide information, education and peer support. OII Australia is a not-for-profit company, recognised by the Australian Taxation Office as a charitable Public Benevolent Institution. OII Australia employs no staff and receives no public funding; this means that we have limited capacity to respond to inquiries except those of high significance to our community. Nevertheless, we thank the NHMRC for conducting this consultation; we would be pleased to discuss the content and issues raised in our submission further with the NHMRC should that be possible.

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:

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

and the ethics and permissibility of:

#### **11. Sex selection, and**

**12. Preimplantation genetic diagnosis**, other forms of testing, and selection for particular characteristics.

In particular, we focus our attention on the de-selection of intersex traits. This is a current issue: diagnosis and testing are already possible for numerous intersex traits, such as Androgen Insensitivity Syndrome (AIS), Congenital Adrenal Hyperplasia (CAH), and sex chromosome differences such as 47,XXY and 45,X0. The American Journal of Bioethics devoted much of its Volume 13 issue 10 issue to the subject, published in September 2013<sup>1</sup>.

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

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<sup>1</sup> *American Journal of Bioethics*, Volume 13, Issue 10, 2013.

<http://www.tandfonline.com/toc/uajb20/13/10>, accessed 11 September 2013.

We aim to ensure that NHMRC is aware of legislation, regulations and parliamentary committee findings on intersex status. We discuss the implications of the clinical shift in terminology from intersex to DSD, consider the rationales and impact of prenatal screening for intersex traits, and recent work on the ethics of selection against intersex traits through PGD.

We argue that government recognition of intersex status, and the existence of an active intersex community in Australia, demonstrate that the de-selection of intersex traits through Preimplantation Genetic Diagnosis (PGD) is no more ethical than de-selection on grounds of homosexuality, sex or ethnicity.

### 3. Conclusions and recommendations

Intersex people lead varied and fulfilling lives, making a full and active contribution to Australian society. We believe that intersex traits are a normal human phenomenon, part of the diversity of human experience. We believe that de-selecting pre-embryos and embryos with intersex traits is no different from de-selection on grounds of sex, ethnicity or, should testing become available in future, sexual orientation or gender identity.

#### Recommendations:

- 1. Intersex traits be clearly referenced by the National Health and Medical Research Council as intersex traits, and not as “disorders of sex development”.**
- 2. Intersex traits be removed from definitions of genetic defects or genetic disorders applicable to Assisted Reproductive Technologies, Preimplantation Genetic Diagnosis, Polar Body Biopsy/Pre-Conception Genetic Diagnosis, and later foetal testing.**
- 3. The close entanglement of intersex status, gender identity and sexual orientation in social understandings of sex and gender norms, and in medical and medical sociology literature, be noted.**
- 4. Selection on the basis of intersex traits and characteristics be prohibited.**
- 5. Parents should be given information showing the reality of intersex lives, and the existence of physical and social sex and gender diversity.**

### 4. Legislation and regulatory recognition of intersex status

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

In February 2013, the Senate’s Legal and Constitutional Affairs Committee stated on the Exposure Draft of the 2012 *Human Rights and Anti-Discrimination Bill* that it supported the creation of an attribute called “*intersex status*”, distinct from the previously proposed “*gender identity*” attribute:

*7.17 The committee agrees with the evidence presented by Organisation Intersex International Australia, and other submitters, that intersex status is a matter of biology rather than gender identity, and as such should not be covered within the definition of gender identity in the Draft Bill. Further, the committee considers that the current requirement in the Draft Bill that intersex individuals identify as either male or female is misguided, and is unhelpful for intersex individuals whose biological characteristics do not necessarily accord with a male or female identification.<sup>2</sup>*

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<sup>2</sup> Senate of Australia, Legal and Constitutional Affairs Committee, February 2013, *Exposure Draft of*

From 1 August 2013, the *Sex Discrimination Act* was amended to include three new attributes: sexual orientation, gender identity and intersex status. In contrast to the other new attributes, intersex status is a biological attribute:

*intersex means the status of having physical, hormonal or genetic features that are:*  
*(a) neither wholly female nor wholly male; or*  
*(b) a combination of female and male; or*  
*(c) neither female nor male.<sup>3</sup>*

Intersex status is explicitly not defined as a third gender or sex, nor is it defined as a gender identity or a form of disability. Intersex is explicitly not a third gender classification<sup>4</sup>.

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

*An intersex person may have the biological attributes of both sexes or lack some of the biological attributes considered necessary to be defined as one or the other sex. Intersex is always congenital and can originate from genetic, chromosomal or hormonal variations. Environmental influences such as endocrine disruptors can also play a role in some intersex differences. People who are intersex may identify their gender as male, female or X.<sup>5</sup>*

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

The *Aged Care (Living Longer Living Better) Act 2013* recognises “lesbian, gay, bisexual, transgender and intersex people” as a special needs category, alongside other groups such as “people from culturally and linguistically diverse backgrounds”, “veterans”, “people who are financially or socially disadvantaged”.<sup>6</sup>

The Australian Charities and Not-for-profits Commission recognises that beneficiaries of not-for-profit organisations may include: “Gay, lesbian, bisexual, transgender, intersex persons”<sup>7</sup>

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

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*the Human Rights and Anti-Discrimination Bill 2012*, [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Legal\\_and\\_Constitutional\\_Affairs/Completed%20inquiries/2010-13/antidiscrimination2012/report/index](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed%20inquiries/2010-13/antidiscrimination2012/report/index), accessed February 2013.

<sup>3</sup> ComLaw (2013) *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013*, <http://www.comlaw.gov.au/Details/C2013A00098>, accessed 22 April 2014.

<sup>4</sup> *Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013*, Explanatory Memorandum, p. 12.

<sup>5</sup> Attorney General's Department (2013) *Australian Government Guidelines on the Recognition of Sex and Gender*, <http://ag.gov.au/Publications/Pages/AustralianGovernmentGuidelinesontheRecognitionofSexandGender.aspx> accessed 1 July 2013.

<sup>6</sup> ComLaw (2013) *Aged Care (Living Longer Living Better) Act 2013*, <http://www.comlaw.gov.au/Details/C2013A00076> accessed 22 April 2014.

<sup>7</sup> Australian Charities and Not-for-profits Commission (2014) *Annual Information Statement 2013: Organisation Intersex International Australia Limited*, <http://www.acnc.gov.au/AIS?ID=7C4EEABF-34C7-4155-A034-F833A9128ACE&noleft=1>

of our intersex status, but also to increasing awareness of our existence and our contributions to society.

## 5. Intersex traits and DSD

In 2006, a clinician “consensus statement” replaced the term intersex with Disorders of Sex Development in clinical settings<sup>8</sup>. This has proved controversial ever since, and the term intersex is itself now more widespread than in 2006, as can be seen from recent legislation and regulation.

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

*Medical professionals needed to maintain their authority in the face of intersex activism, and they did so linguistically through a reinvention of the intersex diagnosis. The new DSD terminology constructs "sex" as a scientific phenomenon, and a binary one at that... This places intersexuality neatly into medical turf and safely away from critics of its medicalization.*<sup>9</sup>

Morgan Holmes states that the terminology shift “reinstitutionalises clinical power to delineate and silence those marked by the diagnosis”<sup>10</sup> Georgiann Davis states “A medical condition is only as real as its definition”<sup>9</sup>. The significance of terminology is further elucidated by Professor Jeff Nisker in his article *Informed Choice and PGD to Prevent “Intersex Conditions”* in the American Journal of Bioethics. He writes:

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

*Once a difference becomes a medical disorder to which the medical profession is dedicating time and resources to prevent, procedures to this end become endowed with appropriateness*<sup>11</sup>

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

*Many – if not most – persons with intersex conditions lead healthy and fulfilled lives.*<sup>12</sup>

Likewise, Davis comments:

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<sup>8</sup> Houk, Hughes, Ahmed, Lee, Writing Committee for the International Intersex Consensus Conference Participants (2006) *Summary of Consensus Statement on Intersex Disorders and Their Management*, in *Pediatrics*, doi:10.1542.peds.2006-0737, <http://www.pediatrics.org/cgi/doi/10.1542/peds.2006-0737> accessed 21 November 2012.

<sup>9</sup> Georgiann Davis (2011) “DSD is a perfectly fine term”: reasserting medical authority through a shift in intersex terminology, in *Advances in Medical Sociology*, Vol. 12, 2011, p. 178.

<sup>10</sup> Morgan Holmes (2011) *The Intersex Enchiridion: Naming and Knowledge in the Clinic*, in *Somatechnics*, Vol. 1(2): 87-114. DOI: 10.3366/soma.2011.0026.

<sup>11</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.

<sup>12</sup> Jason Behrmann and Vardit Ravitsky (2013) *Queer Liberation, Not Elimination: Why Selecting Against Intersex is Not “Straight” Forward* in the *American Journal of Bioethics*, 13:10, 51-53, <http://www.tandfonline.com/doi/full/10.1080/15265161.2013.828131>, accessed 11 September 2013.

*...many people with intersex traits are leading full and happy lives. In our community you will find an assortment of parents, partners, and folks with vibrant careers. Many have not allowed the shame and stigma to taint their lives. Others have made the intersex trait an important piece of their identity. Some publicly push boundaries about sex and gender (and even sexuality)... what I've found in my research is that a major source of the social and psychological harm originates in the medical profession and could be prevented with open, honest, and accurate communication and information.<sup>24</sup>*

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

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

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

The Swiss National Advisory Commission on Biomedical Ethics issued a report on intersex in November 2012<sup>13</sup>

We present the recommendations of the Senate Committee:

*Recommendation 1:*

*"The committee recommends that governments and other organisations use the term 'intersex' and not use the term 'disorders of sexual development'"*

*Recommendation 2:*

*The committee recommends that health professionals and health organisations review their use of the term 'disorders of sexual development', seeking to confine it to appropriate clinical contexts, and should use the terms 'intersex' or 'differences of sexual development' where it is intended to encompass genetic or phenotypic variations that do not necessarily require medical intervention in order to prevent harm to physical health.<sup>14</sup>*

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

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

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<sup>13</sup> Swiss National Advisory Commission on Biomedical Ethics (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

<sup>14</sup> Senate of Australia (2013) *Involuntary or coerced sterilisation of intersex people in Australia*, report of the Community Affairs References Committee.

*This terminology has also now been adopted in Commonwealth Government guidelines to be applied by all Commonwealth agencies.*

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

We recommend that the NHMRC adopt the recommendations of the Senate Community Affairs References Committee and use the term intersex rather than “DSD”, including but not limited to this review of ethical guidelines for use of assisted reproductive technologies.

## 6. Sex chromosome differences

Sex chromosome differences include triploidy, such as 47,XXY (often diagnosed as Klinefelter Syndrome), and monosomy, 45,X or 45,X0 (often diagnosed as Turner Syndrome or Gonadal dysgenesis). The World Health Organization acknowledges:

*The high frequency of individuals with SCA [Sex chromosome anomalies] is due to the fact that their effects are generally not as severe as autosomal abnormalities and are rarely lethal. Indeed, most cases of SCA are compatible with normal life expectancy and often go undiagnosed.<sup>15</sup>*

A 2010 Consensus statement on diagnosis and clinical management of Klinefelter syndrome reports “only 25% of estimated cases are diagnosed post-natally, and <10% are detected at or before birth”.<sup>16</sup> The health impacts of 47,XXY and 45,X0 are typically considered to be cognitive differences, infertility and differences in stature and physical appearance. In some cases there are concurrent health problems.

Many persons with 47,XXY are presently diagnosed late due to fertility issues. Fertility issues for people with 47,XXY are starting to become more manageable, particularly in diagnosis before puberty.

With this low diagnosis rate, it is likely that the commonly stated health impacts of an extra sex chromosome are overstated. The overwhelming majority of persons with 47,XXY do not come to the attention of clinicians because they do not meet the clinical parameters that indicate a need for karyotype testing.

Despite these low rates of diagnosis, termination rates for 47,XXY once diagnosed during pregnancy are known to reach up to 88%.<sup>17,18</sup> The framing of this diagnosis as a major genetic disorder thus has a dramatic impact on the percentage of pregnancies carried to term. We believe that this impact far outweighs the largely benign consequences of sex chromosome differences.

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<sup>15</sup> World Health Organization (undated) *Gender and Genetics*, at Genomic resource centre, <http://www.who.int/genomics/gender/en/index1.html>, accessed 22 April 2014.

<sup>16</sup> A. F. Radicioni, A. Ferlin, G. Balercia, D. Pasquali, L. Vignozzi, M. Maggi, C. Foresta, A. Lenzi (2010) *Consensus statement on diagnosis and clinical management of Klinefelter syndrome* in *Journal of Endocrinological Investigation*, December 2010, Volume 33, Issue 11, pp 839-850

<sup>17</sup> Texas Department of State Health Services (2005) *BIRTH DEFECT RISK FACTOR SERIES: Klinefelter Syndrome*, <http://www.dshs.state.tx.us/birthdefects/risk/risk19-klinefelter.shtm>, accessed 28 September 2014.

<sup>18</sup> Céline M Girardin, Guy Van Vliet (2011) *Counselling of a couple faced with a prenatal diagnosis of Klinefelter syndrome*, in *Acta Pædiatrica*, Foundation Acta Pædiatrica 2011 100, pp. 917–922, DOI: 10.1111/j.1651-2227.2011.02156.x, <http://onlinelibrary.wiley.com/doi/10.1111/j.1651-2227.2011.02156.x> accessed 26 April 2014.

OII Australia believes that sex chromosome differences such as 47,XXY, 45,X0 and similar variations must not be framed as genetic defects, and should not be de-selected on that basis.

## 7. Congenital adrenal hyperplasia

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

The 2006 clinician “consensus statement” defined psychosocial therapeutic rationales for “*early reconstruction*” (that is, cosmetic surgeries on the genitals of infants) as including “*minimizing family concern and distress*” and “*mitigating the risks of stigmatization and gender-identity confusion*”.

With a recognition of intersex status, and gender identity and sexual orientation as attributes in anti-discrimination law in Australia, these rationales for surgical intervention should, in our view, no longer be considered acceptable. However, treatment for intersex traits is not limited to post-natal surgical intervention, it also includes prenatal hormone treatment, and embryo selection.

The case of Congenital adrenal hyperplasia (CAH) demonstrates that prenatal testing is similarly based upon the stigmatization of intersex status, gender identity, gender expression, and sexual orientation.

A 1990 peer-reviewed article by Heino Meyer-Bahlburg entitled, *Will Prenatal Hormone Treatment Prevent Homosexuality?* appeared in the Journal of Child and Adolescent Psychopharmacology. Meyer-Bahlburg considered how research on intersex differences could be used to explore the potential “*prenatal hormone screening or treatment for the prevention of homosexuality*”<sup>19</sup>. While his research showed the “*scientific groundwork*” to be “*insufficient*” at that time, prenatal screening and treatment of intersex traits continues.

In 2010, Professors Alice Dreger and Ellen Feder, with lawyer Anne Tamar-Mattis reported<sup>20</sup> on a 1999 clinical paper by Meyer-Bahlburg that problematizes the gender expression and sexual orientation of people with CAH:

*CAH women as a group have a lower interest than controls in getting married and performing the traditional child-care/housewife role. As children, they show an unusually low interest in engaging in maternal play with baby dolls, and their interest in caring for infants, the frequency of daydreams or fantasies of pregnancy and motherhood, or the expressed wish of experiencing pregnancy and having children of their own appear to be relatively low in all age groups.*<sup>21</sup>

This research on CAH involves use of a steroid, dexamethasone, to modify the behaviour, gender expression and physical expression associated with CAH; dexamethasone has no impact on associated adrenal gland insufficiency, so prenatal treatments are aimed at

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<sup>19</sup> Heino Meyer-Bahlburg (1990) *Will Prenatal Hormone Treatment Prevent Homosexuality?* in Journal of Child and Adolescent Psychopharmacology, 1990/1991, 1(4): 279-283. doi:10.1089/cap.1990.1.279. <http://online.liebertpub.com/doi/abs/10.1089/cap.1990.1.279> accessed 12 July 2013.

<sup>20</sup> Alice Dreger, Ellen K. Feder, Anne Tamar-Mattis (2010) *ioethics Forum blog - Preventing Homosexuality (and Uppity Women) in the Womb?* At Hastings Center Bioethics Blog, <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4754>, accessed 18 May 2012.

<sup>21</sup> H. F. L. Meyer-Bahlburg (1999) *What Causes Low Rates of Child-Bearing in Congenital Adrenal Hyperplasia?* in *The Journal of Clinical Endocrinology & Metabolism*, Volume 84 Issue 6 | June 1, 1999, <http://press.endocrine.org/doi/full/10.1210/jcem.84.6.5718>, accessed 18 May 2012.

cosmetic and social adjustment only, not the serious health consequences associated with adrenal insufficiency and salt wasting.

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

*Gender-related behaviors, namely childhood play, peer association, career and leisure time preferences in adolescence and adulthood, maternalism, aggression, and sexual orientation become masculinized in 46,XX girls and women with 21OHD deficiency [CAH]. These abnormalities have been attributed to the effects of excessive prenatal androgen levels on the sexual differentiation of the brain and later on behavior... We anticipate that prenatal dexamethasone therapy will reduce the well-documented behavioral masculinization.*

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

*While Sparrow draws stark distinctions between sex, gender, and sexual orientation, these concepts are actually intertwined on many levels. Parental choice against intersex may thus conceal biases against same-sex attractedness and gender nonconformity.<sup>12</sup>*

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

## 8. Ethics of PGD for intersex traits

In *Gender Eugenics? The Ethics of PGD for Intersex Conditions*, Robert Sparrow of Monash University remarks, in the context of intersex conditions:

*PGD threatens to become a form of “gender eugenics,” wherein advanced medical technology is deployed to prop up heterosexism by preventing the birth of those with non-normative anatomies ... PGD for intersex conditions raises a set of complex and interrelated questions about disability, the concept of the normal, and the appropriate response to social norms in decision making about the best interests of children<sup>22</sup>*

### Intersex and concepts of normality

Robert Sparrow argues that it is permissible to de-select “severe” traits, requiring some form of medical intervention. However, concepts of normality are subjective, culturally determined, and even impacted by profession and gender.

For example, Welmoed Reitsma *et al* conducted a multi-centre study of 210 physicians in the Netherlands in 2009. The scale of this study, significantly larger than any study of intersex patients, examined the dispositions of general practitioners, gynaecologists and plastic surgeons to refer or perform a surgical labia minora reduction. 164 physicians completed the survey, carried out with a “five-point Likert scale appraisal of four pictures showing a vulva, each displaying different sizes of labia minora”.

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<sup>22</sup> Robert Sparrow (2013) *Gender Eugenics? The Ethics of PGD for Intersex Conditions*, in *The American Journal of Bioethics*, 13:10, 29-38, DOI: 10.1080/15265161.2013.828115, <http://dx.doi.org/10.1080/15265161.2013.828115>, accessed 20 September 2014.

*Questions were posed concerning physicians' personal predisposition to the vulvas, with regard to naturalness, attractiveness (i.e., the extent of appealing), the physician's private ideal (i.e., the overall preference), and what the physician believed to be society's ideal. Skin color, pubic hair growth, potential irregularities, and asymmetries were comparable among the pictures, thereby eliminating potential biases...*

*Almost all of the participating plastic surgeons (90.7%; 39/43) and the majority of the gynecologists (58.5%; 24/41) had performed a labia minora reduction procedure in their clinical practice.<sup>23</sup>*

The survey results indicated:

- *Ninety percent of all physicians believe, to a certain extent, that a vulva with very small labia minora represents society's ideal (2-5 on the Likert scale).*
- *More plastic surgeons regarded the picture with the largest labia minora as distasteful and unnatural, compared with general practitioners and gynecologists.*
- *Irrespective of the woman's labia minora size and the absence of physical complaints, plastic surgeons were significantly more open to performing a labia minora reduction procedure than gynecologists.*
- *Male physicians were more inclined to opt for a surgical reduction procedure than their female colleagues.<sup>23</sup>*

The study found that:

*the opinions of general practitioners and gynecologists, on the one hand, and those of plastic surgeons, on the other hand, diverge when considering what constitutes a natural-looking and attractive vulva. Moreover, this survey clearly reveals that gender of the physician is a significant influence: male physicians in all specialties are more inclined to perform the surgical procedure, compared with their female colleagues.<sup>23</sup>*

The Senate Community Affairs References Committee commented that:

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

and

*3.128 ... Normalising appearance goes hand in hand with the stigmatisation of difference.<sup>14</sup>*

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

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

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<sup>23</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.

*Because the medical profession, not the intersex trait itself, is a major source of the social and psychological harm that perpetuates intersex stigmatization and the “hostile social environment” that individuals with inter-sex traits encounter, justifying PGD by pointing to such negative outcomes is ill-advised and a circular logic.<sup>24</sup>*

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

*Given current trends toward acceptance of sexual and gender minorities (the “Queer community”), we encourage further reflection regarding intersex minorities whose well-being is not medically questionable but rather dependent on their social inclusion.<sup>12</sup>*

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

*6.30 ... The medical understanding of intersex is so strongly focussed on binary sex and gender ... Enormous effort has gone into assigning and ‘normalising’ sex: none has gone into asking whether this is necessary or beneficial.*

We believe that intersex traits are a normal human phenomenon, part of the diversity of human experience, and we hope that one impact of the new legislative and regulatory environment will be to encourage greater social acceptance. We believe that concern about normality and the variable “severity” of intersex traits are not issues that should be acceptable grounds for de-selection of pre-embryos and embryos with intersex traits.

We do not believe that, as intersex people, we are afflicted, defective or deficient.

### **Risks associated with being intersex**

Aside from previously reported risks associated with potential gender identity and sexual orientation, there are clear physical risks associated with some intersex traits, such as a reported higher risk of gonadal cancers. In suggesting that de-selection of intersex traits might be ethical, Robert Sparrow points to such risks. However, sociology professor Georgiann Davis argues:

*In actuality, the risks associated with various intersex traits vary substantially from study to study, leaving us to act on (what might be misguided) predictions about health risks rather than scientific facts.<sup>24</sup>*

Indeed, the Senate Committee inquiry found hard evidence on cancer risks difficult to establish, despite considerable investigation of this issue in collaboration with Australian and overseas clinicians:

*4.28 ... The complexity and diversity of cancer risk can become oversimplified, potentially elevating the perceived or communicated risk. Alternative monitoring options may be overlooked.<sup>14</sup>*

The Committee clearly established that issues around cancer risk were closely entangled with non-physical risks:

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<sup>24</sup> Georgiann Davis (2013) *The Social Costs of Preempting Intersex Traits*, in *The American Journal of Bioethics*, 13:10, 51-53, <http://dx.doi.org/10.1080/15265161.2013.828119>, accessed 11 September 2013.

*The committee is concerned that other matters such as 'sex of rearing' or 'likelihood of gender dysphoria' are interpolated into the discussion of cancer risk...*

*4.39 ... clinical intervention pathways stated to be based on probabilities of cancer risk may be encapsulating treatment decisions based on other factors, such as the desire to conduct normalising surgery... Treating cancer may be regarded as unambiguously therapeutic treatment, while normalising surgery may not. Thus basing a decision on cancer risk might avoid the need for court oversight in a way that a decision based on other factors might not. The committee is disturbed by the possible implications of this.<sup>14</sup>*

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

## De-selection and diversity

In his analysis of the acceptability of de-selection of intersex traits, Robert Sparrow asserts that loss of diversity would be acceptable; a purported lack of community shows a negligible loss of diversity:

*It is ... much less plausible to object to a reduction in the number of children born intersex, as a result of PGD, on the grounds that this would jeopardize a distinctive "way of life" or "culture."<sup>22</sup>*

In contrast, intersex scholar Georgiann Davis remarks of Robert Sparrow:

*I'm left wondering if he is at all familiar with the intersex community. Individuals with intersex traits force society to disentangle sex and gender, and in the process, open up new possibilities for embracing all sorts of human diversity. The recourse of using PGD to select against intersex traits would eventually lead to an obliteration of a community whose members take pride in their bodies and identities.*

*The intersex community is only "invisible" (Sparrow 2013) to those who choose to ignore it; thus, using PGD to select against intersex traits is not somehow different from selecting for race or sexuality (if that were a possibility)<sup>24</sup>*

Davis gave numerous US examples of an intersex community, but Australia's intersex community is also increasingly visible. Intersex people in Australia include the world's first publicly-known intersex mayor, Tony Briffa (also a vice-president of OII Australia). Intersex people are software developers, engineers, teachers, doctors and psychologists, photographers, artists, filmmakers, mothers and foster parents. As part of our increasing visibility we have won significant legislative and regulatory change, and recognition of our health issues by the Senate.

In Australia, the existence of an intersex community, and of increasing recognition of social diversity in sex and gender roles and expressions is evident.

Sparrow exhibits significant discomfort with his own analysis that considers permissible the de-selection of pre-embryos and embryos both with "severe" traits requiring medical intervention, and those for whom intersex differences are merely cosmetic:

*The idea that the development of PGD would lead to a world of "perfect babies" has been a long-standing trope in discussion of this technology. The rapid proliferation of conditions for which PGD is being used, its use to prevent the birth of children with predispositions to disease rather than with genetic disorders (Spits et al. 2007), and the contemporary philosophical enthusiasm for PGD for enhancement as well as therapy (Harris 2007; Savulescu 2001; Silver 1999) all serve to sustain and intensify this concern. The prospect of PGD for intersex conditions is, I think, particularly disturbing in this context for two reasons.*

*First, sexual anatomy plays a key role in the organization of gender and other aspects of human behavior that are central to social life and individual well-being... gender identity and psychological well-being are typically connected to the shape of one's genitals ... The project of normalizing sexual anatomy therefore seems more fraught than that of normalizing other aspects of human anatomy insofar as it would involve a reduction of diversity of a more significant kind...*

*Second, the prospect of PGD for intersex conditions that do not jeopardize the physical health of those born with them immediately highlights the possibility that the same arguments that might be used to justify selection against intersex conditions could also be used to justify selection against homosexuality, should genetic influences on same-sex-attractiveness be identified. "Intersex" was after all originally a classification used to describe those whose gender and/or patterns of sexual preferences rather than anatomies could not easily be classified as male or female. For many critics, including myself, this is a line in the sand that must not be crossed when it comes to the ethics of PGD. Selection on the basis of sexual anatomy seems to tread perilously close to this line...<sup>22</sup>*

Sparrow concludes by suggesting that permitting PDG de-selection of intersex traits has significance for "other nonpathological human variations":

*This is an uncomfortable conclusion because, as I noted earlier, the same considerations that argue for the moral permissibility of PGD for intersex conditions that do not threaten the physical health of individuals also bear on the ethics of PGD to select against other nonpathological human variations. The prospects of human diversity more generally, in the face of the normalizing power of PGD, are therefore linked to the future of intersex.<sup>22</sup>*

Given the legislative and regulatory context, and the degree to which issues of gender identity, sexual orientation and intersex are so closely intertwined, we believe that intersex status, as with sexual orientation and gender identity, falls across Sparrow's line in the sand; selection on the basis of sex characteristics should not be permitted.

## **9. Counselling and information giving**

Behrmann and Ravitsky recommend that parents receive:

*information showing the reality of intersex people leading fulfilled lives, as well as the existence of clinical and social biases against diversity in sex, gender and sexual orientation that may influence decisions about the future well-being of their offspring.<sup>12</sup>*

This recommendation sits well with analysis in this paper regarding conceptions of disorders, normality and increasing social acceptance. OII Australia concurs with this recommendation, and recommends to NHMRC that all parents receive positive information showing the ability of intersex people, and other minorities, to lead happy and fulfilling lives.

Recommended citation: Morgan Carpenter (30 April 2014) Submission on the Review of Part B of the Ethical Guidelines for the Use of Assisted Reproductive Technology in Clinical Practice and Research, 2007, Sydney, Organisation Intersex International Australia. <http://oii.org.au/25621/submission-ethics-genetic-selection-intersex-traits/>