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For intersex human rights, information, and peer support

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

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1. Introduction

Intersex is a term which relates to a range of 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 clearly defined as one or the other sex. Intersex is always congenital and can originate from genetic, chromosomal or hormonal variations. It is a relatively widely understood umbrella term for a large number of variations such as Androgen Insensitivity Syndrome (AIS), 5 alpha Reductase (5aRD), Congenital Adrenal Hyperplasia (CAH), 47,XXY (sometimes called Klinefelter Syndrome), complex Hypospadias, Gonadal Dysgenesis, Vaginal Agenesis, Mayer-Rokitansky-Küster-Hauser syndrome (MRKH). We recognise too that not every intersex person has a clear aetiological diagnosis as the genetic basis of every intersex variation is not yet understood¹.

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. OII Australia employs no staff and receives no public funding.

Every individual member of OII Australia has experienced some form of non-consensual medical intervention, including:

- Pressure to conform to gender norms and to be a “real man” or “real woman”.
- Involuntary gonadectomy (sterilisation) and/or clitoris removal or reduction as an infant, child or adolescent.
- Medical and familial pressure to take hormone treatment.
- Medical and familial pressure to undertake genital “normalisation” surgery.
- Surgical intervention that went outside the terms of consent, including surgery that was “normalising” without consent.
- Disclosure of non-relevant medical data to third parties without consent.
- Being paraded in front of large numbers of medical students.

Recent months have seen major, welcome advances, with federal protection for intersex people on grounds of “intersex status”, changes to Medicare, and federal guidelines on recognition of sex and gender. Further, latest developments overseas include relevant hearings, publications and statements, including by the Swiss National Advisory Commission

¹ Olaf Hiort, 2013, *I-03 DSDnet: Formation of an open world-wide network on DSD* at clinician conference, “4th I-DSD Symposium”, June 2013: “DSD comprise a heterogeneous group of differences of sex development with at least 40 different entities of which most are genetically determined. An exact diagnosis is lacking in 10 to 80% of the cases”, http://www.gla.ac.uk/media/media_279274_en.pdf, accessed 1 July 2013.

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on Biomedical Ethics, the Council of the European Union, German government policy on birth certificates, the UN Special Rapporteur on Torture, and US National Institutes for Health. A US court case will soon be heard to test the constitutionality of unnecessary medical intervention on a South Carolina infant. These developments, and the increased interest and scrutiny that they represent, have influenced the context for this Inquiry.

This further submission to the Senate inquiry examining sterilisation and the sexual health of intersex people seeks to summarise and clarify some key issues arising from previous submissions, with addition of material from recent medical papers and presentations.

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3. Statements of our principles

- 3.1. We wish to live in a society where we are not obliged to conform to sex and gender norms, where our biological distinctiveness is not treated as if it's shameful, or an errant behaviour, where we are protected despite our innate differences, and where intersex people are also not singled out or "othered" as a class, or treated as subjects for experimental treatments. We wish to live in a society where our bodies are not problematized, where our sex assignments are mutable, and where, as adults, we can choose to remain silent on the matter of our sex.
- 3.2. We do not believe access to specific sex or gender assignments by intersex infants, children, adolescents or adults should be reflected in specific anatomical characteristics. We believe that assignments in identification documents, such as birth certificates, should be easily mutable and not require surgical or hormonal intervention.
- 3.3. Medical intervention should not assume crisis in our difference, nor normalisation as a goal. Intervention, especially for "psychosocial" reasons, associated with stigma and familial or social distress, must be viewed in a human rights context. The framework for medical intervention should ensure that we have the same human rights as other members of the community.
- 3.4. We believe that cosmetic genital surgeries, and the sterilisation of children who are assigned a sex that does not match to their gonads, must end. These surgeries have been taking place without adequate scrutiny or regard for patients' human rights. Medical interventions based on psychosocial adjustment or genital appearance should no longer be considered "therapeutic".
- 3.5. Medical, and in particular surgical, interventions must have a clear ethical basis, supported by evidence of long term benefit. We recognise the importance of surgery

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to resolve issues with urination (for example), or to manage significant evidenced risks of cancer. We believe, however, that the lack of any clear medical consensus regarding the actual percentage risk of cancer in many variations, is due in large part to an over-use of sterilisation as a means of “normalising”, or imposing a gender identity on, intersex minors.

- 3.6. Cosmetic and sterilisation surgeries have been taking place without adequate data on outcomes, or long term follow up. Data on intersex adults is largely absent. We believe that sterilisations to manage risk of cancer must be carefully justified and evidenced; we believe that monitoring and accurate aetiological assessment are both practicable and a more acceptable means of managing individual risk – as well as a means of obtaining better quality long term data on risk.
- 3.7. The Victorian health guidelines² present a clinician-led case for the documentation and continuation of existing practice in relation to cosmetic genital surgery and sterilisations, with limited regard for the contributions of community organisations. There is no public documentation for practices elsewhere in Australia, and data (for example on surgery timing) does not appear to be available even to clinician organisations.
- 3.8. It is beyond the current capacity of OII Australia and AISSGA to document current practices elsewhere in Australia. Volunteer representatives of intersex community organisations are not always able to contribute to State and Territory consultations effectively, even to the limited extent sought, for example, by the drafters of the Victorian framework document. Further, in the absence of national policies promoting bodily autonomy and best protection of rights, the existence of inter-State variations enables jurisdiction shopping by parents and clinicians. We believe that these circumstances should not continue.
- 3.9. Long term data is crucial: data must be recorded on intersex births, assignments of sex of rearing, and of surgical and hormonal interventions; psychosocial support must be provided over the long term, including to people who have experienced necessary and unnecessary surgical or hormonal interventions in the past.
- 3.10. We believe that unnecessary “normalising” medical treatment promotes shame, stigma associated with anatomical diversity. It can result in loss of sexual function and sensation, and limits future life options. Necessary medical intervention on minors should preserve the potential for different life paths and identities until the patient is old enough to consent. It should aim to preserve fertility, even if it does not match assigned gender, and preserve the ability to produce hormones.
- 3.11. Medical intervention should be deferred wherever possible until the patient is able to freely give full and informed consent; at an age known as “Gillick competence”. As proposed by the Swiss National Advisory Commission on Biomedical Ethics³, and as with Female Genital Mutilation, unnecessary cosmetic interventions on minors should be criminalised.

² Department of Health, Victoria, 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.

³ Swiss National Advisory Commission on Biomedical Ethics, November 2012, On the management of differences of sex development, Ethical issues relating to “intersexuality, Opinion No. 20/2012”, available in English via <http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en>, accessed 21 November 2012.

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- 3.12. The framework for medical intervention should not infantilise intersex, failing to recognise that we become adults, or that we have health needs as adults, simply due to a lack of long term follow up and non-paediatric research. The Inquiry's first report, in relation to the sterilisation of people with disability, proposed replacing the "best interests of the child" test with a new "best protection of rights" test. We would support the extension of that test to the treatment of intersex minors.
- 3.13. Frameworks for medical intervention must not pathologise intersex through the use of stigmatising language, which in itself has a tendency to further sanction intervention. Frameworks and resourcing should ensure continual dialogue mandated with funded, independent, community intersex organisations.
- 3.14. Government intervention is necessary to ensure the standardisation of therapeutic and non-therapeutic medical protocols and frameworks across Australia, in conformance with human rights objectives.
- 3.15. With one significant exception, LGBT (lesbian, gay, bisexual, trans) or LGBTI organisations lack the experience, expertise and/or capacity to contribute to this inquiry. While we share some common characteristics with LGBT, in our inability to conform to sex and gender norms, our issues are clearly distinct; LGBT and LGBTI organisations shouldn't be expected to deliver intersex-specific services.
- 3.16. Improved psychosocial support, legislation, school curricula, funding for independent intersex organisations to provide information, education and peer support, and the full integration of intersex issues into existing human rights frameworks, should address shame, secrecy, stigmatisation, and discrimination issues, in place of medical interventions. Anti-discrimination legislation is already in place.

4. Previous inquiries

During the course of this Inquiry, we have tabled two human rights or bioethics inquiries into the treatment of intersex people: the 2012 Swiss National Advisory Commission on Biomedical Ethics report on 'intersexuality', and a 2005 City of San Francisco Human Rights Investigation into the Medical "Normalization" of Intersex People. Both reports offer insights for this Inquiry that we would regard as useful.

The San Francisco inquiry found that:

- 1. Infant genital surgeries and sex hormone treatments that are not performed for the treatment of physical illness, such as improving urinary tract or metabolic functioning, and have not been shown to alleviate pain or illness (hereafter referred to as "normalizing" interventions) are unnecessary and are not medical or social emergencies.*
- 2. "Normalizing" interventions done without the patient's informed consent are inherent human rights abuses.*
- 3. "Normalizing" interventions deprive intersex people of the opportunity to express their own identity and to experience their own intact physiology.*
- 4. It is unethical to disregard a child's intrinsic human rights to privacy, dignity, autonomy, and physical integrity by altering genitals through irreversible surgeries for purely psychosocial and aesthetic rationales. It is wrong to deprive a person of the right to determine their sexual experience and identity. ...*

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6. It is ethically wrong to treat people differently or unfairly because they are perceived by others to be “monsters” or “oddities.”⁴

The initial report of this committee into the involuntary or coerced sterilisation made a range of recommendations; we would welcome their application to the case of intersex people. In particular these include a recommendation to replace the existing “best interests of the child” test:

5.126 The committee recommends that all jurisdictions adopt in law a uniform ‘best protection of rights’ test, replacing current ‘best interests’ tests, that makes explicit reference to the protection of the individual’s rights; and the maintenance of future options and choices...

5.121 Specifically, accounting for someone’s best interests must include:

- *Protection of their rights.*
- *Maximising future options and choices.*
- *Decisions to be made on the basis of the best support services available, not whatever services happen to have been provided in the past, which witnesses (including people with disabilities, their parents, and guardians) have frequently told the committee have been inadequate. This is particularly important in the context of the roll-out of Disability Care Australia services.*

5.122 The committee urges jurisdictions, in adopting a best protection of rights test, to be vigilant and ensure it is not undermined by inappropriately broad interpretations of what constitute ‘therapeutic’ cases not requiring tribunal or court consideration. The problem of ambiguity in the interpretation of ‘therapeutic’ was discussed in an earlier chapter, and will be considered further by the committee in a later report on intersex issues.

We regard both the proposed test, and concern about “ambiguity in the interpretation of ‘therapeutic’” as positive developments. In particular, application of the proposed test to intersex would take into consideration the likelihood that an intersex infant or child would be able to provide informed consent once they reach adolescence or the age of majority. We raised concern about the “best interests of the child” test at the 28 March hearing. The matter was explored in the Swiss report in some detail:

There is no guarantee that a decision which is good for the child in its current state will also be best for this person in puberty or adulthood. The Commission recommends that the determination of the child’s welfare should be based as far as possible both on the current interests of the child and on the anticipated interests of the future adult ...

Decisions on sex assignment interventions are to be guided by the questions of what genitalia a child actually requires at a given age (apart from a functional urinary system) and how these interventions will affect the physical and mental health of the child and the future adult . Treatment needs to be carefully justified, especially since – in functional, aesthetic and psychological respects – surgically altered genitalia in DSD are not comparable to natural male or female genitalia...

If such interventions are performed solely with a view to integration of the child into its family and social environment, then they run counter to the child’s welfare.³

We believe that the Swiss report establishes world best practice in the medical treatment of intersex people.

The initial report of this Inquiry also responded to the concerns of the UN Special Rapporteur on Torture in a context which relates to concepts of necessity and therapeutic treatment:

⁴ City and County of San Francisco, 28 April 2005, *A Human Rights Investigation into the Medical “Normalization” of Intersex People*.

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3.30 The report specifically warned against giving 'dubious grounds of medical necessity' priority over a person's legal capacity and right to provide, or withhold, free and informed consent.⁵

The Special Rapporteur on Torture also specifically raised concern about surgeries to “fix” the sex of intersex minors.

5. Clinician recognition of poor outcomes

Two recent submissions by the Australasian Paediatric Endocrine Group (APEG) and the Royal Children’s Hospital, Melbourne ‘DSD’ team (RCH) to the Inquiry offer some admissions:

- an acknowledgement that surgeries take place without adequate data on outcomes
- the recognition that genital “normalising” surgeries on infants, such as clitoral “reduction”, take place without adequate long term follow-up
- and without adequate data on the timing of surgery.
- A strong likelihood that the lack of documentation and data reflects a wide range in surgical practices across Australia.

We explore these issues in more detail below.

6. Surgical outcomes

A lack of evidence supporting good surgical outcomes for explicitly *cosmetic* (appearance-related) surgeries:

...we acknowledge that outcomes related to current approaches remain to be established. (RCH⁶, p.7)

There is limited evidence reporting long-term outcomes of early surgical management for reasons of appearance. The few outcome studies reported have conflicting results of good and poor outcomes (cosmetic, sexual, or psychological), with particular concern regarding sexual function and sensation. (APEG⁷ p.4)

In our fourth submission we noted that these the surgeries involved are cosmetic, with the likelihood that perceptions of good outcome are based on cosmetic appearance. Creighton in the British Journal of Urology International, 2004, supports this assertion, in an analysis of early feminisation surgery, including both vaginal and clitoral surgeries:

Surgery has been regarded as the cornerstone of treatment for virilized female infants and parents. Immediate cosmetic results can be good and this may relieve the concern of both parents and clinicians. However, there is very scanty evidence of a satisfactory postpubertal cosmetic or anatomical outcome. Surgical revision of the vagina to allow tampon use and intercourse is necessary in most patients. If vaginal surgery were deferred it would limit the total number of operations for each individual and may reduce the substantial risk of fibrotic introital stenosis. It is [also] now unacceptable to claim that clitoral surgery does not affect sexual function⁸

⁵ OHCHR, 1 February 2013, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, Juan E. Méndez, http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf, accessed 7 February 2013.

⁶ Submission of the Royal Children’s Hospital, Melbourne “DSD” team submission to the Senate Inquiry into the Involuntary or Coerced Sterilization of People with Disabilities in Australia. July, 2013.

⁷ Submission of the Australasian Paediatric Endocrine Group (APEG) to the Senate Inquiry Into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development. 27 June, 2013.

⁸ S Creighton, 2004, Long-term outcome of feminization surgery: the London experience, British

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Parents have been put in the position of providing consent without being fully informed. The Victorian Health Guidelines state that:

In some cases parents report not having been given adequate information, time or options to provide informed consent or make informed decisions on behalf of their children.²

Regrettably, we do not perceive that this situation has changed. We note that information in the public domain, such as analysis and quotations attributed to a leading clinician in *The Age* newspaper, directly conflicts with outcome assessments by APEG and the RCH:

Associate Professor Sonia Grover, director of the department of gynaecology at the Royal Children's Hospital, says studies show girls with CAH would identify as females and want to have periods and sex later in life and that surgery done early produced good results. All infant surgery is conducted with the informed consent of parents.

"While we have the data to say they are going to end up identifying as females ... and we have evidence that surgical outcomes are good, and sensory outcomes and sexual function are good, where's the pressure to change the practice?" Grover says.⁹

This conflicting data and the lack of realistic information provision has an adverse impact on parents' ability to give informed consent. The self-professed skill of a particular surgeon in one State provides no basis for a rational, national, human rights-based approach to cosmetic genital surgeries on intersex infants.

We presented a critique of the treatment of a minor with 46,XX CAH in our second submission, referring to a case mentioned by the Chief Justice of the Family Court in her submission to this Inquiry. The child's genitals were feminized in infancy, according to standard protocols for CAH still current in Victoria. Family Court approval for sterilization was obtained in adolescence, alongside a changed sex of rearing; the initial surgical assignment turned out to be inappropriate. The sterilisation was approved to "normalise" the suicidal adolescent, bringing his body more closely into line with his gender identity, rather than to manage any cancer risk – and thereby removing his fertility for essentially social reasons. The two conflicting sets of surgical procedures in this case demonstrate the potentially traumatic and life limiting impact of treatment protocols for CAH in girls, and an inappropriate use of sterilisation that only appeared before the courts because of the change in sex of rearing. The core features of this case are just as likely to reoccur today.

The Victorian Health guidelines also state:

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.²

We do not perceive any change in sensation-related outcomes, the rationales for surgery, or its timing, or in the regard for preservation of alternative life paths as a result of this framework document applicable in a single State. The APEG report, for example, presents *only* "psychosocial" rationales in its justification for cosmetic and sterilisation "normalisation"

Journal of Urology International 93 Supplement 3, 44-46, <http://onlinelibrary.wiley.com/doi/10.1111/j.1464-410X.2004.04708.x/abstract>, accessed 2 February 2012.

⁹ The Age, 20 June 2013, *It takes more than two*, <http://www.theage.com.au/national/it-takes-more-than-two-20130619-2oj8v.html>, accessed 20 June 2013.

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surgeries, contrary to the opinion of the Swiss Biomedical Ethics report. APEG support surgery for:

psychosocial reasons such as to allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing.

As stated in our fourth submission, we believe that it is not reasonable to dismiss cases of intersex people changing sex of rearing, or later sex assignment as a patient identity issue, of gender dysphoria. Poorly evidenced clinical approaches, and disregard for data on changes in lived sex, bear responsibility for surgically assigning an incorrect sex and limiting later life options.

In previous submissions we have detailed the rationales for psychosocial surgeries, questioned the assertions and case study evidence for cancer risk, and presented extensive details of pilot studies into the problematic sexual function and sensation outcomes of genital surgeries. We have seen no data on surgical methods and approaches in Australia outside Victoria, other than references in the APEG submission.

7. Practitioner concern about ethics of intersex genital surgery on minors

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

Warne and Professor Sandberg, Director of the Division of Child Behavioral Health in the Department of Pediatrics and Communicable Diseases at the University of Michigan, were both contributors to the 2006 “Consensus” statement¹⁰, so this critique co-authored by Sandberg of an ethics paper co-authored by Warne represents a very significant difference in interpretation of that document.

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

Many have now recognized that the central challenge in DSD care is not centered on the surgeries per se, but rather finding a way to help families (and healthcare professionals) overcome the shame and anxious secrecy that may shape minds and force hands in ways that ultimately harm all involved...¹¹

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

The authors appear to assume ‘that conditions for good ethical decision-making [...] are already in place’. And yet the environment for shared decision making [5] – the highly integrated, interdisciplinary healthcare team that includes behavioral health services called for in the DSD consensus [2] – that makes possible such good decision-making remains elusive...¹¹

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

¹¹ A Dreger, D Sandberg, E Feder, 2010, *Ethical Principles for the Management of Infants with Disorders of Sex Development*, in *Hormone Research in Paediatrics*, Horm Res Paediatr 2010;74:412–418, DOI: 10.1159/000316940, <http://www.karger.com/Article/Pdf/316940>, accessed 7 July 2013

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

The authors have opted to ignore the existing DSD ethics literature in an effort to arrive at principles putatively unburdened by previous ethical engagement.¹¹

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

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

Dr Mika Venhola, a Deputy Chief of the Oulu University Hospital Department of Pediatrics and Adolescence, Finland¹² has recently spoken out on intersex issues. He says that:

The treatment paradigm of intersex conditions is debatable and clinicians are in confusion as to the best management of intersex.¹³

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

When I was training to become a paediatric surgeon I was taught how to do these, let's say, corrective, in parentheses, "corrective" cosmetic surgeries, and at that time it was not allowed to criticise your elders, and it was impossible to voice out then my expression or thoughts on this one. But when I was doing my first intersex surgery due to cosmetic reasons I felt it was such a huge human rights violation, and especially the children's rights violation, that I swore I will never do this when I am independent and can decide for myself. And I have never done it, since then. It kind of struck me so hard that it is not right...

It's time to stop and think... And this is the part of growing up, to see that surgery is not the solution to everything. It is a saying that, "if you give a surgeon a hammer, every problem is a nail". And I'm trying to see the screws also.

There are patients that will do much better without surgery. And I as the surgeon do not lose anything there; I don't have to do surgery... [I am] trying to figure out the patients who benefit from my surgical skills and who are the patients I should not operate, who would do better with some other treatment or no treatment at all¹⁴

In a conference statement in October 2012, Venhola stated:

..the gender of the [intersex] child is an educated guess and entails a great risk of error. The atypical genitals of babies with intersex conditions are not a health risk but early genital surgery is performed for aesthetic or social purposes. Genital surgery seeks to produce genitals that match the supposed gender of the infant. The advocates of surgery consider this mandatory but controversy exists. Some authorities consider cosmetic surgery on babies as genital mutilation. There are no controlled studies of the efficacy of surgery over conservative and supportive care to enable good sexual function, quality of life, and parental bonding. The techniques of surgery are infested with poor long-time results and redo surgery is very likely.

¹² See Oulu University Hospital staff page <http://www.oulu.fi/pediatr/staff.htm>, accessed 13 August 2013.

¹³ Mika Venhola, "Intersex: Ambiguous Genitals Or Ambiguous Medicine?" October 2012. <http://www.nocirc.org/symposia/twelfth/symposium12.pdf>, accessed 13 August 2013.

¹⁴ Bonobo3D, 8 April 2013, Transcription of Paediatric Surgeon Mika Venhola on INTERSEX, on YouTube, <http://www.youtube.com/watch?v=riNtxjntqZE&feature=youtu.be>, accessed 12 April 2013.

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Intersex genital surgery is not without problems. The management of intersex conditions is based on expert opinion, and evidence on proper treatment is lacking. Intersex is also an ethical problem as full disclosure, informed consent, and children's rights are not unquestionably respected.¹³

He summarises his position thus:

Why operate on the child's body if the problem is in the minds of the adults?¹⁴

In our first submission we quoted Anne Tamar-Mattis of Advocates for Informed Choice in the US, writing in Psychology Today:

There's a theory floating around the world of medicine that goes like this: while it is widely known that patients with [intersex variations] are unhappy with the treatment they have received – cosmetic genital surgery, unwanted hormone treatment, and humiliating genital exams top the list – they can be safely ignored because there is actually a "silent majority" of patients out there who are doing just fine. This is a comforting idea. It justifies the mistakes of the past, and it allows current practice to continue without all the discomfort of change.

... But no one can find them. After almost two decades of patient advocacy and active debate, decades in which hundreds of affected people have spoken out against the treatment they received, not one person ... has spoken out publicly to say that normalizing treatment is just great. Not one.

But there is a silent majority out there in the world of DSD treatment. And I have found them. They are the clinicians, the researchers, the junior practitioners, the social workers, the nurses, the psychologists who know or suspect that there is something very wrong with current treatment models, but keep their thoughts to themselves.¹⁵

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

Surgical intervention... I don't think that should be done. I would not think that would be an immediate priority. ... The problem with surgical intervention is once it's done, you can't change your mind 12 years later, when this child suddenly shows far more traits of being female and um, well, no probably more the other way, showing far more traits of being male, and you have taken away everything, that could enhance some sort of maleness in this child. So I think personally I would leave surgical, I wouldn't touch surgical not as a child... even if the genetics were all saying 'boy' or all saying 'girl'; I still think that it is something that as an infant, I don't think that is all that important; because it is physical, and it is not going to change the way a baby or a small child is going to be. And it is irreversible and you cannot do anything about it.¹⁶

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

¹⁵ Anne Tamar-Mattis, 30 October 2012, *The Dex Diaries, Part 9: The Real Silent Majority*, at *Psychology Today*, <http://www.psychologytoday.com/blog/fetishes-i-dont-get/201210/the-dex-diaries-part-9-the-real-silent-majority>, accessed 7 February 2013.

¹⁶ Chris Somers xxy, Tracy Reibel and David Whyatt, 2008, *Intersex and Androgyny And Implications for Provision of Primary Health Care*. Geraldton, WA: Combined Universities Centre for Rural Health. Available on <http://www.curch.uwa.edu.au>

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*You have already done irreversible surgery so you can't go backward, and at the same time you have made somebody a boy and then she thinks she could have been better off as a girl, you can't go back. That's why they say that the best approach and in my opinion and that within society is you do minimal surgery and give that gender assignment in childhood and then wait until the child himself is between sixteen to eighteen...*¹⁶

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

*... my understanding is that that the medical profession does not do gender reassignment surgery on young babies anymore because of the adverse affects it has had on adults... adults who have been raised as a particular gender and they could not identify with their gender often ended up with committing suicide or having you know..., very sort of intense mental health problems as a result,... um my guess, you know you, my job is to support people given options, and mini choices, like giving information, um, but I will tend to say well you know, it's a very difficult decision to make, to support them... because it's and once you hit the good, bad, ultimately it's the child who should decide what they want to be when they get older.*¹⁶

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

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

8. Claims of improved surgical techniques

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

...we acknowledge that outcomes related to current approaches remain to be established. (RCH¹⁷, p.7)

However, while practices in relation to diagnosis, technology, surgical techniques, patient information and disclosure have improved significantly, decision-making about healthcare remains challenging. (Victoria Health Department²)

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

*It is often argued that the results of genital surgery carried out 15 or 20 years ago should be interpreted cautiously. The recent consensus statement on the management of 21-hydroxylase deficiency states there is reason for optimism that future outcomes will be better with current surgical techniques [9]. Although five of the six patients had initial surgery 15 years earlier, one (no. 6) had initial surgery only a year before the study and yet showed markedly abnormal results in temperature and vibration sensation in the clitoris. We are unaware of any data which show that the outcome is improved with modern techniques.*¹⁸

¹⁷ Submission of the Royal Children's Hospital, Melbourne “DSD” team submission to the Senate Inquiry into the Involuntary or Coerced Sterilization of People with Disabilities in Australia. July, 2013.

¹⁸ N.S. Crouch, C.L. Minto, L.-M. Liao, C.R.J. Woodhouse and S.M. Creighton, 2004, *Genital sensation after feminizing genitoplasty for congenital adrenal hyperplasia: a pilot study*, in *British Journal of Urology International* 93, 135–138 doi:10.1046/j.1464-410X.2004.04572.x, <http://www.ncbi.nlm.nih.gov/pubmed/14678385>, accessed 18 November 2012

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

[Hospital] response protocol should differentiate between “medically necessary” and “cosmetic.” Simply arguing that the surgeries are better now is beside the point because the surgeries are medically unnecessary.⁴

Surgical outcomes on newborns and infants may not become apparent until the child becomes a teenager or adult, and will persist for a lifetime – yet there is no long term follow up to properly assess this, or provide support to affected people.

9. Data and long-term follow up

There is a clinician acknowledged lack of data, long term support and follow-up:

Current international guidelines recommend long-term follow-up of children with DSD who have early surgery. This does not occur in Australia, as there is no co-ordinated registry regarding the management and outcomes for people with DSD. (APEG⁷ p.6)

A major concern in medical management, both in Australasia and internationally, is with deficient psychosocial support, particularly as the young person with DSD becomes older. (APEG p2)

...follow-up studies to assess the impact of our current approaches on outcomes in various subgroups of DSDs are required. (RCH⁶, p.7)

Improvements in care for individuals with DSD will not occur without improvements in clinical service provision and research. (APEG p.7)

These are, in our view, structural failings; the issues that we have brought before the Inquiry are not new concerns. They have been in the public domain since at least the David Reimer case in 1997, the 2005 San Francisco Human Rights Investigation, and efforts from the mid 1990s for the intersex community to engage with clinicians. These failings directly impact upon the health of intersex adults, and they are not addressed in the Victorian decision-making framework.

We fear that the persistent lack of data and follow up represents a lack of will, oversight and scrutiny, rather than a clinical lack of resources. We note, however, that both Australian intersex community organisations are volunteer run, with volunteer resources; as suggested by the UN Special Rapporteur on Torture, we believe that this represents a structural inequality that we hope the Senate may seek to address.

Both APEG and RCH DSD submissions acknowledge a lack of adequate data and consensus on the timing of surgery – and even a lack of data on current practices within Australia.

International medical guidelines exist to define the level of genital ambiguity at which surgery is indicated, however the guidelines state that the optimal timing of surgery remains debatable. This is because there is a lack of strong evidence to either support or refute specific recommendations on timing. (APEG p.4)

International guidelines define the degree of virilisation for which surgery may be indicated; however the optimal timing of this surgery is not known [4]. This is because there are no data to support one particular approach (e.g. surgery in early infancy) over another (e.g. surgery in late infancy, mid-childhood, early adolescence or late adolescence). At RCH, surgery is most commonly performed in infancy. (RCH, p.6)

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Although some people advocate leaving all genital surgery till later when the person can consent themselves to the procedure, there are no studies to demonstrate a comparison of outcomes with this greater delay[6, 7]. (RCH, p.6)

Directly related to these issues, there's no data on actual clinical practice in Australia yet:

We are in the process of performing a study of the recommendations on surgical timing across the clinicians in our organisation. (APEG p.5)

This absence of data still persists after several decades of surgical intervention and contention.

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

Care of adults with DSD poses many challenges not least because most information in the field is based entirely based on paediatric experience. There is little guidance for making an accurate diagnosis in adults with a female phenotype who might present... Furthermore, the group of women often over that age of 25 for whom paediatric care might not have been transparent in terms of accurate diagnostic information, may have a legacy [of] psychological issues that hinder engagement with medical services.

In a world where individuals attending an adult DSD service are often highly informed experts in the field, the role of medical care is often to guide on safety aspects and accept that the evidence base from which conventional practice has developed is questionable. One example of this area is the practice of gonadectomy for women with complete androgen insensitivity syndrome for whom there is very little data in adults¹⁹

The work of Schützmann et al, referenced in our second submission, discussed the psychological implications of earlier treatment. A pilot study of 37 adults, 36 of whom had undergone genital and/or gonadal surgeries, revealed that:

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.²⁰

10. Practitioner controversy around hormonal intervention

Significant controversy also exists around hormonal intervention. We understand that prenatal hormone intervention is available in Australia to promote behavioural and cosmetic changes in fetuses with 46,XX CAH. The CAH Support Group Australia website discusses these, in a manner which fails to address its controversy and ethical issues:

If you or your partner has any form of CAH, your children might also have it. If you are pregnant and there is a history of CAH in your family, your doctor may recommend that you have an amniocentesis or chorionic villus sampling. These tests can diagnose CAH before your baby is born. If your baby has CAH, your doctor can give you medicine to treat

¹⁹ Gerard Conway, 2013, Paper presented to clinician conference I-DSD, *I-18 The practical management of an adult at risk of gonadal tumourigenesis*, http://www.gla.ac.uk/media/media_279274_en.pdf, accessed 1 July 2013.

²⁰ Schützmann, K. et al, February 2009, Psychological Distress, Self-Harming Behaviour, and Suicidal Tendencies in Adults with Disorders of Sex Development, in *Archives of Sexual Behaviour* 38(1):16-33, <http://link.springer.com/article/10.1007%2Fs10508-007-9241-9>, accessed 7 February 2013.

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*your baby even before he or she is born. Treatment should begin as soon as possible once CAH is diagnosed.*²¹

This experimental prenatal treatments has a history that can be traced back through the following papers.

Heino Meyer-Bahlburg, published "*Will Prenatal Hormone Treatment Prevent Homosexuality?*" in the *Journal of Child and Adolescent Psychopharmacology* in 1991, linking intersex to homosexuality, using intersex as a means of experimentation around sexual behaviour in humans:

*The prenatal hormone theory of sexual orientation is derived from research on lower mammals, and draws limited corroboration from human research on endocrinological abnormalities associated with physical manifestations of intersexuality. Its application to the more common forms of homosexuality has led to conflicting findings and major controversy. The scientific groundwork is insufficient to support the introduction of prenatal hormone screening or treatment for the prevention of homosexuality.*²²

Heino Meyer-Bahlburg was later published in "*What Causes Low Rates of Child-Bearing in Congenital Adrenal Hyperplasia?*", in the *Journal of Clinical Endocrinology & Metabolism*, where he constructed a higher than typical incidence of tomboyish behaviour, homosexuality, and non-traditional gender roles in 46,XX CAH as abnormal:

*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.*²³

We presented a critique of the use of dexamethasone in our first submission to this Inquiry.

11. Practitioner controversy around non-intersex surgical procedures

Concern about medical ethics and perceptions regarding normal genitals are not limited to intersex infant and child genitals, but extend to cases of surgery on consenting adults. Reitsma *et al* conducted a multi-centre study of 210 physicians in the Netherlands in 2009. The scale of this study, significantly larger than any study of intersex patients, examined the dispositions of general practitioners, gynaecologists and plastic surgeons to refer or perform a surgical labia minora reduction. 164 physicians completed the survey, carried out with a "five-point Likert scale appraisal of four pictures showing a vulva, each displaying different sizes of labia minora".

Questions were posed concerning physicians' personal predisposition to the vulvas, with regard to naturalness, attractiveness (i.e., the extent of appealing), the physician's private ideal (i.e., the overall preference), and what the physician believed to be society's ideal.

²¹ CAH Support Group Australia, undated, http://www.cah.org.au/v2/index.php?option=com_content&view=article&id=46&Itemid=34, accessed 4 August 2013.

²² Heino Meyer-Bahlburg, *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>

²³ Heino Meyer-Bahlburg, "*What Causes Low Rates of Child-Bearing in Congenital Adrenal Hyperplasia?*", *The Journal of Clinical Endocrinology & Metabolism* June 1, 1999 vol. 84 no. 6 1844-1847 doi: 10.1210/jc.84.6.1844, <http://jcem.endojournals.org/content/84/6/1844.full>

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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.²⁴

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.²⁴*

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.²⁴

The study team felt it possible that surgical trends are informed by trends in the pornography industry and media, including use of image manipulation.

In our view, the study reveals both a gendered bias, and the absence of standard objective measures for cosmetic perceptions of "normal" female genitals.

12. Sex classification, identification documents and surgeries on minors

The APEG submission presents a conception of sex and gender which we reject as not necessary. It deems surgeries necessary for:

psychosocial reasons such as to allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing.⁷

We do not believe that it is acceptable to make children's bodies match their assigned gender. The fertility of an intersex person should be preserved even if it contradicts the apparent gender assignment.

In our view, such surgeries are precisely the types of surgery meant by the UN Special Rapporteur on Torture:

²⁴ 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.

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77. Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, "in an attempt to fix their sex" leaving them with permanent, irreversible infertility and causing severe mental suffering.⁵

And also by the Council of the European Union when they describe discrimination as including:

medically unnecessary surgery, performed without their informed consent, or that of their parents, in an attempt to 'fix' their sex?²⁵

We believe that the lack of any clear data and medical consensus regarding the actual percentage risk of cancer in many intersex variations, is due in large part to an over-use of sterilisation - particularly as a means of imposing a gender identity on an intersex minor.

While the issues are somewhat different, the slowly growing legal and social acceptance of trans or gender diverse people, including children, who have genitals that do not match their identities, shows that such apparent contradictions are possible.

For the sake of clarity, we would like to acknowledge concerns about moves to create or extend third options for the identification of children on birth certificates. While we fully support the federal government guidelines on recognition of sex and gender, we do so because the identity guidelines:

- Enable adult intersex people to opt for alternatives as a matter of personal choice.
- Create a third option which is not called "intersex", but rather "X", as intersex is a biological characteristic associated with many different preferences as to gender identity.

OII Francophonie (the French-speaking affiliate) reports that non-specific birth certificates are permitted for two years, but this has not led to an abandonment of surgery; the impending classification of an infant with a binary gender prompts surgical intervention.

IVIM/OII Germany describes current legislative proposals for a mandatory blank, birth certificate for infants who meet specific physical criteria. IVIM/OII Germany translate the German Bundestag reports as follows:

In the future it will be possible to leave the gender specification in the birth registry open for children who are born without a clear gender...

(3) If the child can be assigned to neither the female nor the male sex, then the child is to be entered into the register of births without such a specification.²⁶

IVIM/OII Germany believes that this creates great risks of stigmatisation:

Instead of leaving sex registration open for all, and not just intersex children, once again special rules are created, which produce exclusions. The living conditions of the vast majority of intersex people will not improve as a result²⁶

²⁵ Council of the European Union, 24 June 2013, "Guidelines to Promote and Protect the Enjoyment of All Human Rights by Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Persons" document number 11492/13, <http://register.consilium.europa.eu/pdf/en/13/st11/st11492.en13.pdf>, accessed 27 June 2013.

²⁶ IVIM/OII Germany, 15 February 2013, *Sham package for Intersex: Leaving sex entry open is not an option*, at OII Europe, <http://oiieurope.org/bluff-package-for-inter-leaving-sex-entry-open-is-not-an-option/>, accessed 16 February 2013.

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The German proposals are opposed by three national intersex organisations, with one describing them as “silly season fantasies”²⁷.

OII Australia shares the position of our autonomous German and French sibling organisations: we do not call for a third option for children’s birth certificates. Despite the existence here of important new anti-discrimination legislation on the grounds of “intersex status”, that we would regard as a prerequisite for such actions, we regard this as premature to say the least.

We support the easy mutability of gender and sex markers on identification documents. We also support adult options for non-binary identification. We prefer scenarios that do not single out intersex people for special identification on the grounds of our biology; OII Francophonie regard this as a form of “purification” of male and female categories.

In relation to the German birth certificate proposals, OII Australia secretary Morgan Carpenter joined with IVIM/OII Germany’s Dan Ghattas and Silvan Agius of ILGA Europe to write an opinion piece in Der Spiegel pointing out:

...no reporter has yet asked how this will effectively improve quality of life for intersex people, particularly when cosmetic genital surgeries on infants are set to continue.

*In short, while there may be some limited benefits from the new German law, real progress for intersex people is not measured through the number of available labels but through an end to the human rights breaches currently being inflicted.*²⁸

Suggested citation

Carpenter, M (2013) *August submission to the Senate Inquiry on the involuntary or coerced sterilisation of people with disabilities*, Sydney, Organisation Intersex International Australia. <http://oii.org.au/23387/august-submission-senate-inquiry-sterilisation>

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²⁷ OII Australia, 20 August 2013, *German proposals for a “third gender” on birth certificates miss the mark*, <http://oii.org.au/23183/germany-third-gender-birth-certificates/>, accessed 20 August 2013.

²⁸ Silvan Agius, Morgan Carpenter, Dan Ghattas, 22 August 2013, *Third Gender: A Step Toward Ending Intersex Discrimination in Der Spiegel*, <http://www.spiegel.de/international/europe/third-gender-option-in-germany-a-small-step-for-intersex-recognition-a-917650.html>, accessed 22 August 2013.