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

15 February 2013

1. What is intersex?

Intersex is a term which relates to a range of natural biological traits or variations that lie between "male" and "female". An intersex person may have the biological attributes of both sexes or lack some of the biological attributes considered necessary to be defined as one or the other sex. Intersex is always congenital and can originate from genetic, chromosomal or hormonal variations. Historically, the term "hermaphrodite" was used, originating in classical mythology. The term intersex was adopted by science in the early 20th century.

In the interests of clarity, intersex is not the same as transgender, or transsexuality. Trans people include people who are *born unambiguously* one gender but who, later in life, identify and present in the world differently. In contrast, intersex is not based on identity, even though non-standard identities might be regarded as a logical possible consequence of non-standard anatomies. Unlike trans people, intersex people are diagnosed visually, at birth, or via amniocentesis, by chromosome, and other blood tests.

Fausto-Sterling (2000) reports that 1-2% of the population are intersex[1]. The NSW Ministry of Health reports data from the NSW *Mothers and Babies* report showing that infants with visible reportable differences of sex anatomy between 2003-2009 comprised 0.59% of all births, while no breakdown of additional (often not visible at this stage) relevant chromosomal "anomalies" is given[2]. Intersex differences may also be determined during infancy, at puberty, when attempting to conceive, or through random chance.

2. OII Australia

Organisation Intersex International Australia Limited (OII Australia) is a national body by and for intersex people. We promote the human rights of intersex people in Australia, and provide information, education and peer support.

OII Australia is a not-for-profit company, recognised by the Australian Taxation Office as a charitable institution. It is funded entirely out of the voluntary contributions of its member. OII Australia employs no staff and receives no public funding. OII Australia is the Australian affiliate of a global network of intersex organisations, and a member of the National LGBTI Health Alliance.

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[1] Anne Fausto-Sterling, 2000, *Sexing the Body: Gender Politics and the Construction of Sexuality*, Basic Books, ISBN 0465077145, 9780465077144.

[2] NSW Ministry of Health Centre for Epidemiology and Research, 31 October 2011, *NSW Mothers and Babies 2009*, NSW Public Health Bulletin Supplement, http://www0.health.nsw.gov.au/pubs/2011/mothers_babies_2009.html, accessed 3 December 2012.

3. Our interest in this submission

This is a submission in respect of an investigation into the involuntary or coerced sterilisation of people with disabilities in Australia by the Senate Standing Committee on Community Affairs.

The World Health Organization (WHO) defines “disabilities” as:

> *…an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.*
>
> *Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.*[3]

The WHO definition applies to intersex, in that the medical profession regards intersex people as having an impairment ("disorder") in body function or structure, “disorder of sex development”. These “disorders” are regarded as impairments in our body structures (genitals, gonads, chromosomes) or functions (adrenal glands, gonads, or other glands).

Intersex people are medicalised, stigmatised and suffer discrimination due to our distinctive biological characteristics. Intersex variations affect perceptions of our realness as men or women, and society still generally requires people to live and identify as male or female. As a result, intersex bodies do not meet societal expectations and intersex people experience homophobia and prejudice. Cultural, familial and medical attitudes towards our differences from sex norms govern which sex we are assigned, and what surgical and other medical interventions will be made to ensure we conform to those norms. Medical interventions seek to erase intersex differences.

The terms of reference for this senate investigation include and investigation of sterilisation treatments, including:

> *… treatments that prevent menstruation or reproduction, and exclusion or limitation of access to sexual health, contraceptive or family planning services;*

The investigation is also exploring issues around consent and the adequacy of legal frameworks:

> *(d) whether current legal, regulatory and policy frameworks provide adequate:*
> *(i) steps to determine the wishes of a person with a disability,*
> *(ii) steps to determine an individual's capacity to provide free and informed consent,*
> *(iii) steps to ensure independent representation in applications for sterilisation procedures where the subject of the application is deemed unable to provide free and informed consent, and*
> *(iv) application of a 'best interest test' as it relates to sterilisation and reproductive rights*[4]

The terms of reference have been updated to explicitly include the sexual health and

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[3] World Health Organization, 2013, *WHO | Disabilities*, http://www.who.int/topics/disabilities/en/, accessed 5 February 2013.

[4] Senate Committees – Parliament of Australia, undated, The involuntary or coerced sterilisation of people with disabilities in Australia, http://aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/involuntary_sterilisation/tor.htm, accessed 4 February 2013.

reproductive issues associated with intersex people:

> *2. Current practices and policies relating to the involuntary or coerced sterilisation of intersex people, including:*
>
> *(a) sexual health and reproductive issues; and*
>
> *(b) the impacts on intersex people.*

The nature of many intersex variations means that many of us are not fertile, however, infertility is often *iatrogenic* – a result of medical intervention. We wish to take this opportunity to highlight issues around non-consensual medical treatment, with a particular focus on medical interventions that affect our gonads, potential fertility, and sexual health.

OII Australia thanks the Senate Standing Committee on Community Affairs for investigating these issues which are of pressing and direct relevance to intersex people in Australia.

We also wish to thank People with Disability Australia Inc., for clarifying the scope for our participation in this inquiry.

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5. Surgical "normalisation" and sterilisation

Experiences of members of OII Australia

Members of OII Australia have a range of medical diagnoses, including Congenital Adrenal Hyperplasia, 47,XXY (often diagnosed as Klinefelter Syndrome), Androgen Insensitivity Syndrome, and other related conditions.

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

- Pressure to conform to gender norms and to be a "real man" or "real woman".
- Involuntary gonadectomy (sterilisation) and clitorectomy (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.

The legal background

In Australia, the ACT Law Reform Advisory Council reviewed Territory arrangements for registering births in a 2012 report that clearly distinguishes between intersex status and a gender identity (our emphasis in second paragraph), and shows how the legal and medical systems require children to be assigned a sex-of-rearing that is "often" confirmed by surgical and other medical intervention:

> *The forms for notification and registration of a birth – 'Notification of Birth not Occurring in a Hospital' (Form 218) and 'Birth Registration Statement' (Form 201) – are legislative instruments that must be complied with. The forms currently require that the sex of a child be marked as either 'male' or 'female'. ... for a child who is known to be intersex at or soon after their birth, the legislation requires a decision must to be made, within short time limits, to record the child's sex within the female/male binary.*
>
> *… it is common for parents, in consultation with medical practitioners, to assign a gender identity to an intersex child; this often involves surgery and medical treatment to 'confirm' the chosen gender identity. The chosen gender identity is the 'sex' that is recorded when formally notifying and registering the child's birth. It will not be known until the child matures whether the assigned sex which was assigned at birth and implemented through surgery and medical treatment, does in fact accord with the child's gender identity.* [5]

State health documents that we have seen further problematize decision making about which binary sex to rear a child, by requiring daily family counselling – up until a sex of rearing is agreed.

Given a social environment where intersex people are stigmatised, we support registration of intersex infants with a binary sex, however, the birth registration process also means that we have no accurate data on our numbers. Further, no data is available to us on the number or type of surgical procedures on intersex children, or the numbers of intersex children involved.

Intersex adults in some states, such as Victoria and NSW, are able to change their birth certification on the basis of the administrative correction of a factual error in the initial document. Victoria permits birth certification correction to show no sex data. In Western Australia, adults have been obliged to undergo reassignment surgery to obtain revised documentation.

The proposed Human Rights and Anti-Discrimination Bill explicitly exclude from protection anyone who fails to identify "on a genuine basis" with either binary sex:

> *87. This clause does not require recognition of, or provision of facilities for, people who do not identify as either sex. Protection against discrimination on the basis of gender identity implements recommendation 43 of the SDA report.*[6]

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[5] ACT Law Reform Advisory Council, March 2012, *Beyond the Binary: legal recognition of sex and gender diversity in the ACT*, http://www.justice.act.gov.au/publication/view/1897/title/beyond-the-binary-legal-recognition, accessed 2 September 2012.

[6] Attorney General's Department, 2012, Human Rights and Anti-Discrimination Bill, exposure draft

The Hon. Diana Bryant AO, Chief Justice of the Family Court of Australia, made a submission, numbered 345, on the *Human Rights and Anti-Discrimination Bill 2012*[7], where page 2, penultimate paragraph, included the following statement: that the Court has jurisdiction to decide applications,

> *… in respect of young people born with an ambiguous or indeterminate sex to undertake medical treatment (surgical or otherwise) that would enable them to have the appearance of a particular sex.*

The legislative approach on rapid decision-making on sex assignments, and a background where people stigmatized due to our variance from gender norms are not considered worthy of protection, reinforces the social and surgical assignment of intersex infants to a binary sex.

2006 medical "Consensus Statement"

The Prader scale[8] divides visible genitalia into seven categories, with male and female categories at either end which are considered "normal". The current protocols for the treatment of intersex people are laid out in a 2006 *Consensus Statement on Intersex Disorders and Their Management*. Until the 2006 *Consensus Statement*, all genitals that did not conform to male or female norms were surgically altered so that they cosmetically appear "normal". From 2006, the *Consensus Statement* advises surgery:

> *in cases of severe virilisation (Prader III, IV, and V)*

That is, in 3 of those 7 Prader Scale stages, surgery intended to make an infant's genitalia cosmetically appear "normal" is still considered appropriate. If such surgeries were undertaken on, for example, infant girls with "normally" sized clitorises, then our society would consider that to be "infant genital mutilation".

The 2006 Consensus *Summary Statement* includes the following rationales for "early reconstruction" (that is, cosmetic surgeries on the genitals of infants) as:

> *"minimizing family concern and distress"*
> *"mitigating the risks of stigmatization and gender-identity confusion".* [9]

These issues are often referred to as "psycho-social" adjustment, in that they do not relate to any necessary intervention required for physical reasons, such as the ability to urinate. Rather, they relate to the individual's position in a family and in society, and in relation to social expectations of the individual's role in those environments.

"Gender-identity confusion", and social and family concern, justify cosmetic and gonadal interventions that impact on intersex people from infancy and throughout our lives.

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explanatory notes, http://www.ag.gov.au/Humanrightsandantidiscrimination/Australiashumanrightsframework/Pages/ConsolidationofCommonwealthantidiscriminationlaws.aspx, accessed 26 November 2012.

[7] Submission on the Human Rights and Anti-Discrimination Bill 2012 by The Hon Diana Bryant, AO, Chief Justice of the Family Court, https://senate.aph.gov.au/submissions/comittees/viewdocument.aspx?id=129543e5-fd82-46bb-8a2d-e11002f46f90

[8] Eunice Kennedy Shriver National Institute of Child Health and Human Development (USA), undated, *Prader Scale*, https://science.nichd.nih.gov/confluence/download/attachments/23920688/Prader_Scale.pdf, accessed 6 February 2013.

[9] 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.

Surgical sterilisation of intersex people, via removal of gonads, is mandated in Australia in many circumstances, on the basis of a risk of cancer, and we present evidence below to show that the levels of risk identified are inflated and generalised.

Surgical cosmetic "normalisation" and involuntary sterilisation are the most serious issues of concern to the intersex community generally, and to OII Australia specifically.

Report of the Swiss National Advisory Commission on Biomedical Ethics

The Swiss National Advisory Commission on Biomedical Ethics published a globally significant document on intersex in November 2012[10]. We highly commend this document to the senate. It is notable for a range of reasons:

- It makes a clear apology for damage done to intersex people in the past, and up until the present.
- It makes a case for criminal sanction for non-medically necessary genital surgeries.
- It makes a strong case against medical intervention solely for "psychosocial" reasons.

We present some of the findings of the Commission on "psychosocial" rationales for medical intervention. The emphasis is the Commission's:

> ***Especially delicate are those cases where a psychosocial indication is used to justify the medical urgency of surgical sex assignment in children who lack capacity. Here, there is a particularly great risk of insufficient respect being accorded to the child's (future) self-determination and its physical integrity****…*
>
> ***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 … are not comparable to natural male or female genitalia.*
>
> *Decisions are to be guided, above all, by the child's welfare…*
>
> *The harmful consequences may include, for example, loss of fertility and sexual sensitivity, chronic pain, or pain associated with dilation (bougienage) of a surgically created vagina, with traumatizing effects for the child.* ***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.*** *In addition, there is no guarantee that the intended purpose (integration) will be achieved.*

Further, the Commission states:

> *…on ethical and legal grounds, all (non-trivial) sex assignment treatment decisions which have irreversible consequences but can be deferred should not be taken until the person to be treated can decide for him/herself*[10]

We fully support these findings.

[10] 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.

Current protocols in Australia are still based on psychosocial adjustment: minimising family concern, and mitigating the risks of stigmatisation due to physical difference.

UN Special Rapporteur on Torture

The UN Special Rapporteur on Torture stated on 1 February 2013 in *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez*:

> *76. … There is an abundance of accounts and testimonies of persons being denied medical treatment, subjected to verbal abuse and public humiliation, psychiatric evaluation, a variety of forced procedures such as sterilization, State-sponsored forcible … hormone therapy and genital-normalizing surgeries under the guise of so called "reparative therapies". These procedures are rarely medically necessary, can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma (A/HRC/14/20, para. 23).*
>
> *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…*
>
> *79. The mandate has noted that "members of sexual minorities are disproportionately subjected to torture and other forms of ill-treatment because they fail to conform to socially constructed gender expectations.*[11]

The Special Rapporteur on Torture calls on member states to:

> *88. The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, "reparative therapies" or "conversion therapies", when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups.*

We hope that this Senate Inquiry will prove an opportunity for the Australian government to act decisively on this call.

6. The case of Androgen Insensitivity Syndrome ('AIS')

Professor Garry Warne and Doctor Jacqueline Hewitt of the Department of Endocrinology and Diabetes, Royal Children's Hospital, Melbourne, Victoria, in a 2009 paper in the *Medical Journal of Australia* demonstrate that gonadectomies remain standard procedure in Australia, on the basis that they are life preserving. Gonadectomies involve the removal of testes and/or ovaries. On gonadectomies, Warne and Hewitt write:

> *They were asked to respond to a proposal — advanced by an advisory committee representing the interests of the gay, lesbian, bisexual, transsexual and intersex communities — that doctors wanting to perform surgery to treat ambiguous genitalia in children too young to consent on their own behalf should have to seek approval from the Family Court of Australia on a case-by-case basis…*

[11] 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.

> *What has largely been missing from the debate is recognition of the fact that surgery forms a necessary part of the risk management strategy for preventing gonadal malignancy. In any DSD ['Disorder of Sex Development'] associated with a Y chromosome, there is an increased risk of germ cell cancer, especially when the testes are intra-abdominal (the risk of seminoma in partial androgen insensitivity is 50% for an intra-abdominal testis) or when there is gonadal dysgenesis.* [12]

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

- *educating parents and patients about risk;*
- *removing all intra-abdominal gonads that cannot be brought down into the scrotum;*[12]

People with Androgen Insensitivity Syndrome (AIS) have bodies that are *completely* insensitive to testosterone and other androgen hormones (CAIS) or *partially* insensitive to androgens (PAIS). A person with AIS has XY sex chromosomes, more typically associated with men, yet their bodies develop partially or mostly along female lines because of the way their body respond to androgens. People with AIS will have testes, rather than ovaries, but their natural external appearance will vary. The overwhelming majority of people with CAIS will be perceived, assigned, raised and identify as women; this is much less clear cut with people with PAIS.

The protocol described by Warne and Hewitt means that the testes of all people with CAIS, and very many with PAIS, are removed in infancy. Alternative views are numerous, including international export Katrina Karkazis[13] or, in the case of AIS specifically, by Quigley et al[14] Batch et al[15], Crouch[16]. The AISSG UK summarise some of the research in this field, showing sampling bias in many studies, and far lower risks for most intersex people with internal gonads, albeit risks that increase with age:

> *An early (1963) study (Morris et al) … estimated a risk of 22% but this is most likely an overestimate, since many of the cases were referred primarily because of the malignancy. A 1992 Danish study reported tumours in 4 of 21 patients but a 1976 study had found no tumours in 23 patients of their own and only 7 tumours in 82 cases gleaned from the literature (8.5%). The risk of such tumours increases with age, the 1976 study (Manuel et al) suggesting an age-related risk of 3.6% at age 25 but approaching 33% at age 50. Two reports from one group (1981 and 1991) estimate the overall risk to be 6 to 9%.*[17]

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

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

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

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

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

[17] Pleskacova J. et al, 17 June 2010, *Tumor Risk in Disorders of Sex Development* in *Sexual Development* Sex Dev, DOI: 10.1159/000314536, http://www.aissg.org/PDFs/Pleskacova-et-al-

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

> *The most numerous are patients with androgen insensitivity syndrome. The overall prevalence of CIS and invasive type II GCT (seminoma and nonseminoma) in this group is estimated to 5.5%. There is, however, an important difference between patients with complete and partial androgen insensitivity syndrome in whom malignancies occur in 0.8% and 15%.*
>
> *Patients with gonadal dysgenesis (with either a 46,XY or 45,X/46,XY karyotype) seem to be the most endangered subgroup, although the prevalence in different series is rather incoherent, being reported in 15–100% of all cases [Slowikowska-Hilczer et al., 2001; Cools et al., 2006a]. After the rational interpretation of available data, Cools et al. [2006a] rated the total occurrence at 12% and possibly at more than 30% if gonadectomy had not been performed.*[17]

The Androgen Insensitivity Support Group (AISSG) UK report:

> *At the 2009 AISSG UK group meeting Dr. Naomi Crouch (gynaecology registrar at the University College Hospital London multi-disciplinary intersex clinic) talked about the cancer/gonadectomy issue, as follows:*
>
> > *Guest speaker Naomi Crouch said that the risk of cancerous changes in CAIS testes is thought to be about 5% by early adulthood and that gonadectomy at age 18 is recommended. The advantage of not doing it in childhood is that the intact testes will facilitate a natural puberty (testosterone from the testes gets converted in the body to oestrogen which promotes breast growth etc.).*[16]

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

> *A group member asked why then aren't breasts removed from young XX women, when the risk of breast cancer in the general population of women is about 8%? Naomi confirmed that the risk of breast cancer in general is about 1 in 12, but it was easier to monitor breast tissue for changes than it is to monitor intra-abdominal testes in AIS women. Ultrasound technicians, for example, do not have so much expertise in terms of knowing what to look for, since these conditions are rare.*[16]

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

The risk assessment by Warne and Hewitt at Melbourne’s Royal Children’s Hospital is a grossly inflated generalisation that does not reasonably take international good practice, or individual circumstances, into account. As a consequence, AIS women routinely have their gonads removed, denying the possibility of a natural puberty, and requiring lifelong hormone replacement therapy, with all its (not yet fully understood) attendant risks.

In addressing the issues raised by Crouch, we believe that technician familiarity should be addressed, in preference to gonadectomy and lifelong HRT.

No patient-specific, nature-identical hormone replacement

We believe that gonadectomies in such cases arise, in large part, from a simple belief that women should not possess testicles: they arise from a pathologisation of sex differences.

Tumour-Risk-2010.pdf, accessed 23 August 2012.

This pathologisation of sex differences for their own sake is evidenced not only by the use of generalised statements of risk, but also by the choice of replacement hormone provided to women with CAIS.

Women with CAIS simply metabolise testosterone differently to other people with XY sex chromosomes. If their testes are retained, women with CAIS can avoid the necessity for any HRT and will go through a natural female puberty, developing female sex characteristics.

Even though testosterone-producing testes are removed, women with CAIS are not offered a nature-identical replacement for the hormone that their bodies produced until gonadectomy; they are only offered oestrogen, the hormone produced by ovaries. This must be because they are classified as women and oestrogen is supposed to be the hormone that women need. Women with CAIS are obliged to conform to sex and gender norms. Indeed, women with AIS who wish to replace the hormone they used to produce with a nature-identical hormone, testosterone, are considered to have “gender identity” issues.

We have reports of women with CAIS who have gone to great lengths to obtain testosterone via their doctors, and who report health benefits.

Broader societal impact

Medical protocols for people with AIS and other forms of intersex may have a national impact. For example, the Sydney Morning Herald reported in 2011 on an interview with Dr Bennett Foddy, “deputy director and research fellow for the program on ethics and the new biosciences at Oxford”:

> *He also notes that such intersex conditions in women are not as rare as you might imagine, especially in female athletes, where such a condition would assist them to rise to the top. It has been estimated that one in 500-600 female athletes have a detectable intersex condition with an XY chromosome (AIS, for example). Many will have an intersex condition, such as CAH, that is undetectable in a chromosome test but confers a distinct advantage.*
>
> *"Over five Olympic Games, an average of one in every 421 female athletes was found to have a Y chromosome," he says.*[18]

Jon Bardin, writing in the Los Angeles Times in 2012, describes the case of Spanish hurdler Maria Jose Martinez-Patiño:

> *A gender test revealed that she had a Y chromosome, which normally makes a person male. She also had complete androgen insensitivity syndrome, or CAIS, which prevented her body from responding properly to testosterone and caused her to develop as a woman.*
>
> *… if testosterone were essential to athletic success, Martinez-Patiño would have been doomed to fail because her body can't use the hormone. Many women with androgen insensitivity have competed in the Olympics, and "the idea that testosterone is a necessary ingredient for elite athletic performance is really undermined by these cases," [University of Michigan biopsychologist Sari] Van Anders said.*
>
> *In fact, androgen insensitivity is overrepresented among female athletes, [Eric Vilain, director of the Center for Gender-Based Biology at UCLA] added: The general population*

[18] Sydney Morning Herald, 8 December 2011, *Venus v Mars*, http://www.smh.com.au/world/science/venus-v-mars-20111207-1oj4i.html, accessed 4 February 2013.

> *has an incidence of 1 in 20,000, but for Olympic athletes it is about 1 in 400. No one knows why.*[19]

Athletes like Maria Jose Martinez-Patiño and South African runner Caster Semenya are not doping; they wish to compete as they were born and raised. And all athletes have a genetic advantage:

> *Foddy argues that Semenya is a vivid illustration of the ways in which natural genetic variation can generate large differences in athletic performance… 'It seems unfair to exclude [these] women just because they have a natural genetic gift,"*

We know that gender test results are of significant interest here in Australia; the first disclosure of data on Caster Semeya, was made by an Australian newspaper. On 11 September 2009, the Sydney Morning Herald ran a story with the salacious headline, "*Secret of Semenya's sex stripped bare*" [20].

Yet we are not aware of any Australian women athletes who have been adversely subjected to gender testing; we know of no Australian women athletes who have been found to have AIS. We believe that medicalising, pathologising treatment protocols for AIS and CAH women (those with Congenital Adrenal Hyperplasia) may be at fault.

7. The case of Congenital Adrenal Hyperplasia ('CAH')

Congenital Adrenal Hyperplasia is a type of intersex affecting the adrenal glands such that people with XX sex chromosomes (typically associated with women) and CAH will experience some degree of prenatal virilisation. The degree of virilisation, or masculinisation, can vary significantly. CAH is also associated with salt wasting, which requires medical attention.

Alice Dreger, Ellen Feder and Anne Tamar-Mattis, in a 2012 paper in the *Journal of Bioethical Inquiry* on the "use of dexamethasone in pregnant women at risk of carrying a female fetus affected by congenital adrenal hyperplasia (CAH)". They found that dexamethasone, a steroid, is being used, off label, to prevent homosexuality and physical masculinization – and this is considered to be of greater benefit than established cognitive and physical risks to the children concerned. They found that:

> *Surprisingly, results from our Freedom of Information Act (FOIA) requests … indicate that the U.S. National Institutes of Health (NIH) have funded New to see whether prenatal dexamethasone "works" to make more CAH-affected girls straight and interested in having babies* [21]

Dreger, Feder and Mattis note that Doctor Maria New, a paediatric endocrinologist who prescribes dexamethasone, in a meeting of the US CAH-diagnosis group "CARES Foundation", displayed a photo "of a girl with ambiguous genitalia and said:

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[19] Los Angeles Times, 30 July 2012, *Olympic Games and the tricky science of telling men from women*, http://articles.latimes.com/2012/jul/30/science/la-sci-olympics-gender-20120730, accessed 7 February 2013.

[20] Sydney Morning Herald, 11 September 2009, *Secret of Semenya's sex stripped bare*, http://www.smh.com.au/news/sport/secret-of-semenyas-sex-stripped-bare/2009/09/11/1252519599453.html, accessed 8 February 2013.

[21] Alice Dreger, Ellen K Feder and Anne Tamar-Mattis, 2012, *Prenatal Dexamethasone for Congenital Adrenal Hyperplasia, An Ethics Canary in the Modern Medical Mine* in *Journal of Bioethical Inquiry, 2012, Volume 9, Number 3, Pages 277-294*, http://www.springerlink.com/content/m1523l7615744552/?MUD=MP, accessed 23 August 2012.

> *The challenge here is … to see what could be done to restore this baby to the normal female appearance which would be compatible with her parents presenting her as a girl, with her eventually becoming somebody's wife, and having normal sexual development, and becoming a mother. And she has all the machinery for motherhood, and therefore nothing should stop that, if we can repair her surgically and help her psychologically to continue to grow and develop as a girl (New 2001a).* [21]

Other notable medical practitioners are also involved in this research and these justifications. In a 1999 paper in the *Journal of Clinical Endocrinology & Metabolism*, titled "*What Causes Low Rates of Child-Bearing in Congenital Adrenal Hyperplasia?*", Heino Meyer-Bahlburg wrote:

> *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.* [22]*0*

Heino Meyer-Bahlburg of Columbia University, the author, is a member of the American Psychiatric Association (APA) working group on revisions to the *Diagnostic and Statistical Manual of Mental Disorders*, revision 5[23]. and a member of the "Standards of Care Revision Committee" (SOC Committee) of the World Professional Association for Transgender Health[24]. The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) and *Standards of Care* (SOC) are the standard protocols in use here in Australia for the medical treatment of adolescent and adult people who are gender non-conforming – unfortunately including intersex people who experience difficulty with their assigned sex of rearing.

Treatment with dexamethasone does not affect the salt wasting associated with CAH, it just affects psychological and physical "virilisation".

Further, treatment with dexamethasone targets the "virilisation" of girl fetuses with CAH but, because it is delivered to "at risk" mothers before amniocentesis testing for CAH, it also affects boys and non-CAH girl foetuses:

> *When compared to controls, "[i]n general, treated children were born at term and were not small for gestational age. As a group, they did not exhibit teratogenous effects/gross malformations, although eight severe adverse events were noted in the treated group, compared with one in the control group. Three children failed to thrive during the first year of life; in addition, one had developmental delay and hypospadias; one had hydrocephalus; two girls were born small for gestational age, and one of these girls was later diagnosed with mental retardation; and one child had severe mood fluctuations that caused hospital admission. In the control group, only one child was admitted because of Down's syndrome …*
>
> *[a]n adverse effect was observed in the form of impaired verbal working memory in CAH-unaffected short-term-treated cases [i.e., the children who were not the intended targets of the intervention]. The verbal working memory capacity correlated with the children's self-*

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[22] Heino Meyer-Bahlburg, 1 June 1999, *What Causes Low Rates of Child-Bearing in Congenital Adrenal Hyperplasia?,* doi: 10.1210/jc.84.6.1844, *The Journal of Clinical Endocrinology & Metabolism* June 1, 1999 vol. 84 no. 6 1844-1847, http://jcem.endojournals.org/content/84/6/1844.full, accessed 4 August 2012.

[23] Heino Meyer-Bahlburg, 2012, *APA DSM5 Work Group Member Disclosure Report*, http://www.dsm5.org/MeetUs/Documents/Sex%20and%20Gender%202011/Meyer-Bahlburg%20-%20Disclosure%20-%204-28-11.pdf, accessed 23 August 2012.

[24] WPATH, 2012, Standards of Care, 7th Version, http://www.wpath.org/documents/SOC%20V7%2003-17-12.pdf, accessed 23 August 2012.

> *perception of difficulties in scholastic ability, another measure showing significantly lower results in CAH-unaffected, DEX-exposed children. These children also reported increased social anxiety. In the studies on gender role behavior, we found indications of more neutral behaviors in DEX-exposed boys*[25]

The prevention of homosexuality and physical masculinisation is considered to be of greater benefit than the established *cognitive and physical risks* to treated children. These are substantial risks that mean that doctors in Sweden have discontinued treatment. Despite these published, reported risks, dexamethasone treatment is still being sold to parents in the US as "safe and effective"[21].

We have attempted for some time to discover whether or not dexamethasone is prescribed "off-label" in Australia. The Department of Human Services is now assisting, from late 2012, via their LGBTI Working Group, however we do not yet have any data.

8. The case of 47,XXY and similar intersex variations

Current protocols for the treatment of intersex people diagnosed as adolescents and adults are problematic, due to:

- Medicalization where an individual does not seek treatment.
- Treatments deemed to be aligned with sex-of-rearing generally proceeding without counselling or support. Such treatments can result in discomfort, especially when they are inadequately patient-centred.
- Treatments that are not aligned with sex-of-rearing result in diagnosis as "disordered" or "dysphoric". Such diagnosis is based on the inaccurate assumption that one set of gender-affirming treatments is necessarily more valid or appropriate than another.

We have examples of this in Australia with people with 47,XXY chromosomes and similar. Women typically have 46 chromosomes, including XX sex chromosomes. Men typically have 46 chromosomes, including XY sex chromosomes. People with 47,XXY chromosomes are born with an extra sex chromosome, and are typically assigned as male at birth and diagnosed as having Klinefelter Syndrome. Doctor John Parkinson, Consultant Psychiatrist, in a paper to the *Australian and New Zealand Journal of Psychiatry*, reports that:

> *47XXY males and other cases of hypogonadism are usually treated with testosterone at adolescence or on diagnosis, often with surgery for gynaecomastia [breast development]. These procedures are usually found helpful in affirming a male gender identity.*[26]

However, he describes a set of case studies of people who:

> *…regretted having had mastectomy and wanted breast reconstruction…*
>
> *These cases give food for speculation as to the relation of body to body image and as to possible antenatal hormonal influence on gender identity. They might also illustrate academic notions of gender fluidity. However, the main purpose of this paper is clinical – a plea for careful assessment of gender identity before launching on physical treatments*[26]

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[25] Hirvikoski, T., A. Nordenström, A. Wedell, M. Ritzén, and S. Lajic. 2012. *Prenatal dexamethasone treatment of children at risk for congenital adrenal hyperplasia: The Swedish experience and standpoint* in *The Journal of Clinical Endocrinology and Metabolism* 97(6). doi:10.1210/jc.2012- 1222, http://jcem.endojournals.org/content/97/6/1881, accessed 24 August 2012.

[26] John Parkinson, 2007?, *Gender Identity in Klinefelter's Syndrome and Male Hypogonadism: Six Cases of Dysphoria*. Paper supplied to study participants. An earlier version of this paper was published as *Gender Identity in Klinefelter's Syndrome and Male Hypogonadism: Four Cases of Dysphoria*, in *Aust N Z J Psychiatry,* January 2007 41: A70, doi: 10.1080/14401614070410s10109. http://anp.sagepub.com/content/41/1_suppl/A70.1.extract, accessed 3 May 2012.

An OII Australia board member says:

> *I was one of Parkinson's cases, I'm hypogonadal and I generally present as masculine, although most of my documentation now doesn't specify a gender. In 2003, I sought a breast reduction, in the hope of better balancing my own understanding of my body with social demands. I'd recently moved for a time to Australia, a much warmer country than where I grew up and, due to my increasing age and the climate, my differences were becoming far more noticeable. Despite written exchanges with the surgeon before the surgery, the reduction turned out to be a mastectomy. Surgical consent statements were ambiguous, although the paper trail leading to surgery is not. A second surgery, provided at no charge by the surgeon, was necessary after just three months, but failed to address my loss of sense of self. The week after the first surgery, I was diagnosed with reactive depression, and this persisted for around three years.*
>
> *I wasn't treated according to my expressed wishes. It was as if the surgeon had done what he thought I must need according to the way I presented. He tried to make me into a 'normal' man, although the scarring and other characteristics about my body belie that.*
>
> *I still struggle with what was done to me, close to a decade later. It was the most difficult period of my life, and led directly to the break-up of a longstanding relationship and employment stress.*[27]

Michael Noble has documented his own experience:

> *Around the age of 23, an endocrinologist discovered that my body had never produced enough testosterone for me to undergo a full puberty. He therefore suggested I commence testosterone therapy. Initially, I resisted the pressures placed on me to commence therapy. Yet, eventually, I crumbled under the constant onslaught of threats and horror stories of what my future would be like if I didn't undergo therapy, which the doctors claimed would turn me into a 'real man'. It was insinuated, even blatantly stated on occasions, that my life would be worthless; that I would be a freak; that I would never achieve my potential, and that I would never have any self-esteem (apparently the self-esteem I already had was invalid as it existed outside of the predefined paradigm of being a real man). So, eventually, from the age of 28, after about 6 years of constant threats and 'counselling' by my medical specialists, I began testosterone therapy. And I found it to be a horrifying experience.*
>
> *Testosterone therapy generated profound and traumatic changes in me. I lost contact with who I was and thus my sense of self. I was mortified when I began to grow large amounts of hair, where hair had never been. My voice dropped. I developed a very strong libido, but found the feelings unwelcome. I lost contact with my heart and the ability to relate to people in a nonsexual manner. Yet, most frustratingly, while I developed a sex drive and ability to sustain an erection, orgasms eluded me. I just couldn't function as a 'normal' male, and this caused me significant psychological and physical distress.*
>
> *Worst of all, however, was that the therapy turned me into someone I was not…*[28]

Michael Noble writes on his experience in discussion with other people with XXY, and about his own body image, as it has changed due to hormone treatment:

> *While it seems that most XXYs receive some degree of benefit from testosterone therapy, my traumatic experience is not unique. Some XXYs who found the attempts to turn them into 'real men' psychologically devastating, have also either ceased, or drastically reduced their testosterone intake. A few report they feel they are more female than male and have sought female sex reassignment…*

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[27] Personal communication to authors.

> *Sadly though, most intersex people cannot completely revert back to their pretherapy states. I only reverted back to about 75% of what I was prior to commencing therapy. While my true self quickly re-emerged after the overwhelming and oppressive weight of the drugs had dissipated, testosterone therapy has irreversibly damaged my body. Therefore, gone are the days when I looked like a teenager, and gone is the slim build and smooth face. These days, fully dressed, I appear very much like a male. I have a deep male voice; my physique generally appears like a slightly overweight male; and I walk, talk and, for the most part, conduct myself as a male.*
>
> *Yet I am more than a male.*[28]

Medical treatment to make him a "real man" has "irreversibly damaged" his body. These body changes – crucially – took place to make his body conform to medical assumptions about an appropriate gender identity and physiology.

Willem de Ronde et al report in the *European Journal of Endocrinology* that "quality of life is reduced in patients with Klinefelter syndrome on androgen replacement therapy[29]. Such therapy is a standard protocol for XXY people.

Chris Somers XXY *et al* also write about the pressure that primary care providers feel to act in such cases, here quoting a public health doctor:

> *I suppose we have such an idea about kids growing up and such a bi-polar idea about males and females and what we expect physically from them, and that I can say it would be pretty tough if we had...a male with Klinefelter who had breasts as they were growing up; that would be very difficult not to do anything.*[30]

9. Surgical outcomes

Surgical intervention typically, as described in the 2009 paper by Warne and Hewitt, takes place on infants. Yet we believe that insufficient attention is placed on the future adult, due to an erroneous belief that intersex can be cured such that it doesn't affect adults. There is a paucity of data on the impact of surgery on adults, and few long term studies: for example, intersex is erased from official documentation through the assignment of a binary sex of rearing. We have seen no long term studies within Australia. In the words of the Swiss National Advisory Commission on Biomedical Ethics:

> *Treatment needs to be carefully justified, especially since – in functional, aesthetic and psychological respects – surgically altered genitalia … are not comparable to natural male or female genitalia.*[10]
>
> *There is a need for representative studies with sufficient numbers of cases and control groups comprising untreated or non-invasively treated … subjects. Data should also be collected on patient satisfaction and on the effectiveness of various treatment methods and surgical sex assignment procedures.*[10]

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[28] Michael Noble, 19 July 2010, *I am me and I am OK*, http://oiiaustralia.com/18138/opinion-michael-noble/, accessed 2 May 2012.

[29] Willem de Ronde, Anne de Haan and Madeleine L Drent, 2009, *Quality of life is reduced in patients with Klinefelter syndrome on androgen replacement therapy*, in *European Journal of Endocrinology* (2009) 160 465-468 ISSN 0604-4643.

[30] 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. http://www.cucrh.uwa.edu.au/images/stories/fellow_reports/Intersex_and_Androgyny_Report_Somers.pdf, accessed 30 March 2012

A cautious approach, deferring surgery until the age of consent, is supported by all the long term evaluative medical studies of which we have had sight. Creighton, for example, states:

> *it is possible to have a good cosmetic outcome and yet still have a vagina too narrow for sexual intercourse. It is also possible to have a good anatomical outcome, i.e. a normal calibre vagina, and yet still have poor sexual outcome. Vaginal stenosis is the main anatomical problem and is common, occurring in 36–100% after surgery in infancy [7,8]. Even after a 'one-stage' genitoplasty, revision at adolescence is frequently necessary and the family should be prepared for this. Revision surgery may be on the clitoris, with up to 44% undergoing clitoral revision [9], or the vagina, with estimates of up to 80% revision rate…*
>
> *Two studies assessed in more detail psychosexual function in intersex women after genital surgery. The first compared 34 women with CAH to their sisters without CAH [17]. The CAH group were less likely than their sisters to be sexually active and more likely to have orgasmic dysfunction (33% vs 0%, respectively). The second study of 19 women with CAH compared them to a control group of women with diabetes [18]. Again, those with CAH had significantly less sexual experience, worse orgasmic dysfunction, and were more likely to report problems with penetration. They attributed their difficulties to their surgery.*[31]

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.*[32]

Birgit Köhler, *et al*report that:

> *Prenatal deficit of androgens or androgen action results in atypical genitalia in individuals with XY disorders of sex development (XY,DSD). XY,DSD include mainly disorders of gonadal development and testosterone synthesis and action. Previously, most XY,DSD individuals were assigned to the female sex. Constructive genital surgery allowing heterosexual intercourse, gonadectomy, and hormone therapy for feminization were often performed. However, outcome studies are scarce.*[33]

This scarcity of outcome studies is a matter of great concern to OII Australia. Those that do exist show that the effects of infant surgeries are long lasting, including a legacy of shame, distorted family dynamics, and insensate genitalia that deeply affect adult relationships and

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

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

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

life satisfaction.

Birgit Köhler *et al* report:

> *Dissatisfaction with function of the surgical result (47.1%) and clitoral arousal (47.4%) was high in XY,DSD partially androgenized females after feminization surgery. Dissatisfaction with overall sex life (37.5%) and sexual anxieties (44.2%) were substantial in all XY,DSD individuals. Problems with desire (70.6%), arousal (52.9%), and dyspareunia [painful intercourse] (56.3%) were significant in XY,DSD complete females. 46,XY partially androgenized females reported significantly more often partners of female (9.1%) or both sexes (18.2%) and dyspareunia (56.5%) compared with controls. Individuals with complete androgen insensitivity syndrome stated significant problems with desire (81.8%), arousal (63.6%), and dyspareunia (70%).*[33]

Finally, there is also a psychological cost, and a core ethical issue. Anne Tamar-Mattis of Advocates for an Informed Choice in the US, and a collaborator in research on the use of dexamethasone treatment for CAH, wrote on both points 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.*
>
> *… I saw this when we raised the alarm about Dr. Dix Poppas, who was doing post-surgical "clitoral sensitivity" tests with vibrating devices on young girls.... I had conversations with doctors around the country about this, and most could see the problem right away. Many of those discussions would go like this:*
>
> > *Doctor: "You're mistaken. No one does that. It would be damaging and unethical."*
> >
> > *Me: "But you see, here is the published study, where Dr. Poppas and colleagues write about doing just that."*
> >
> > *Doctor (looking doubtful): "Well, it was published, so they must have had approval from an ethics board."*
> >
> > *Me: "No, you can see here that they only got approval for chart review." (for looking at the charts after the tests had been done)*
> >
> > *Doctor: "But it was done in a medical setting. So it must not have been harmful. The kids knew it was a doctor doing the testing."*[34]

[34] 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.

Not only is Tamar-Mattis correct in her assertion about the silent majority of intersex people, her criticism of the ethics of testing young girls for clitoral sensitivity, after clitorectomy or clitoral reduction carried out for cosmetic, size-related reasons, goes to the heart of the objectives of this senate inquiry.

Schutzmann notes that research on psychological distress amongst intersex people is "limited by either small sample sizes or lack of standardized measures" as well as "selection bias because the samples consisted only of patients who were treated in a certain medical institution with its specific treatment approach".

In pilot research which attempted to address these concerns through the use of standardized measures across multiple clinics, Schutzmann found that intersex adults report levels of psychological distress at levels that are comparable with traumatized non-intersex women:

> *The prevalence rates of self-harming behavior and suicidal tendencies in the [intersex] sample exceeded the rates of the non-traumatized comparison subgroup [of women], with rates comparable to the traumatized comparison groups of women with physical or sexual abuse* [35]*.*

10. Terminations

CAH and XXY are two of a number of intersex variations which can be discovered through amniocentesis in Australia, and we would like to see data on terminations arising from diagnosis. The Androgen Insensitivity Syndrome Support Group Australia (AISSGA) has obtained limited evidence of terminations for a range of intersex variations dating back to 1989.[36]. We have more recent evidence of terminations for CAH in Western Australia that have significantly reduced the number of live births of people with CAH.

Intersex people include Olympic athletes, a former mayor, professors and doctors of philosophy, and masters of science, engineering and arts. As a rule, people with many intersex variations suffer no mental or social disadvantage. Our physical issues are as much iatrogenic (a product of medical intervention) as they are innate, and are not an intrinsic barrier to our participation in society. We can see no intrinsic reason for intersex variations to be a reason for the termination of pregnancies, yet the description of our variations as genetic disorders or defects promotes such actions.

11. The pathologisation of intersex people as disordered

Current protocols in Australia pathologise intersex people through the use of disordering language, describing intersex variations as 'Disorders of Sex Development' (DSDs) since 2006, despite the continuing use of the term 'intersex' by both national Australian intersex organisations (OII Australia and the Androgen Insensitivity Syndrome Support Group, AISSGA). Protocols in Australia further pathologise intersex people who have difficulty with their assigned sex of rearing as suffering from mental disorders: 'Gender Identity Disorder' or 'Gender Dysphoria'.

The 2012 ACT Law Reform report notes that assignments of a sex-of-rearing,

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[35] Schutzmann, 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.

[36] AIS Support Group Australia, 15 February 2003, *Discrimination against People affected by Intersex Conditions*, submission to the ACT Chief Minister and Department of Justice and Community Safety, http://home.vicnet.net.au/%7Eaissg/Intersex Submission_ACT AISSGA Feb03.pdf, accessed 10 May 2012.

> *often involves surgery and medical treatment to 'confirm' the chosen gender identity [yet] It will not be known until the child matures whether the assigned sex which was assigned at birth and implemented through surgery and medical treatment, does in fact accord with the child's gender identity.* [5]

And the Hon. Diana Bryant AO, Chief Justice of the Family Court of Australia notes the Family Court's role in determining cases brought before it to surgically alter the appearance of intersex children[7].

It is our view that doctors are privileged as experts in counselling with parents, and also in cases taken before the Family Court, while intersex people are absent. The UN Special Rapporteur on Torture comments on this point:

> *29. … Structural inequalities, such as the power imbalance between doctors and patients, exacerbated by stigma and discrimination, result in individuals from certain groups being disproportionately vulnerable to having informed consent compromised*[11]*.*

The rationales for treatment with dexamethasone to counter CAH-related virilisation are particularly shocking, given that homosexuality is no longer pathologised. As noted, a member of the committee that defines medical protocols for gender non-conforming people has written explicitly about CAH women's lack of "interest … in getting married and performing the traditional child-care/housewife role"[22].

A substantial proportion of some intersex groups experience difficulties with assigned sex of rearing. Warne and Hewitt at the Royal Children's Hospital, Melbourne, document research stating that 25% of people with XY forms of intersex experienced issues:

> *The main problem relates to feminising genitoplasty… [which] is much more of a problem in patients with a Y chromosome. For example, one study of 14 adult patients with genetically confirmed partial androgen insensitivity who were treated at Johns Hopkins University in the United States as children, 25% experienced gender dysphoria as adults.*

That "feminising genitoplasty" treatment involved removal of male gonads, clitorectomy, and other cosmetic surgeries to make them appear and have the sexual functions associated with women.

We believe that fear and rejection of naturally-occurring sex differences, and their designation as "disorders of sex development" provide a rationale for surgery and "gender confirming" treatments that also remove the potential for alternative life paths. Having removed that potential, intersex people who are uncomfortable with their designated gender role are inappropriately further disordered, as having Gender Identity Disorder or Gender Dysphoria with treatment protocols from the *Diagnostic and Statistical Manual of Mental Disorders* and *Standards of Care*.

12. Counselling

Medical protocols should focus on counselling and support, and not problematise intersex and gender assignments.

Children will not be aware of the differences about their bodies unless they are made to feel different by their parents and carers, including medical practitioners. Adults should receive full accurate information to enable free, fully informed, prior consent to treatment.

The Swiss National Advisory Commission on Biomedical Ethics report states:

> ***The initial aim of counselling and support is therefore to create a protected space for parents and the newborn, so as to facilitate a close bond. In addition, the parents need to be enabled to take the necessary decisions on the child's behalf calmly and after due reflection. In this process, they should not be subjected to time or social pressures****. Parents' rapid requests for medical advice or for corrective surgery are often a result of initial feelings of helplessness, which need to be overcome so as to permit carefully considered decision-making.*
>
> ***It is important to bear in mind and also to point out to the parents that a diagnosis does not in itself entail any treatment or other medical measures, but serves initially to provide an overview of the situation and a basis for subsequent decisions, which may also take the form of watchful waiting****.*
>
> *…interventions have lasting effects on the development of identity, fertility, sexual functioning and the parent-child relationship.* ***The parents' decisions should therefore be marked by authenticity, clarity and full awareness, and based on love for the child, so that they can subsequently be openly justified vis-à-vis the child or young adult***[10]

We recommend adopting a frequency of medical and psychological follow-up which does not problematize intersex, or the assignment of a gender assignment, but which allows for calm reflection and watchful waiting.

Medical protocols should focus on facilitating a close and loving bond between parents and their child, rather than surgical interventions which may run counter to the integration of a child in a family, and the future adult's interests.

13. Summary and recommendations

In summary, current protocols in Australia involve medical intervention to attempt to make intersex infants' bodies conform to "male" or "female" standards. Medical interventions typically make intersex people sterile. While many of us may be infertile anyway, future medical advances may change that situation.

Inflated generalisations of risk are used to remove gonads, such as the testes of women with AIS. Early intervention or interventions based on inflated risk assessments deny intersex people a natural puberty and make us reliant on lifelong hormone replacement therapy when that would otherwise not be necessary.

Adolescents – and even adults – have also reported feeling pressured, by their parents' and/or doctors' recommendations to conform to societal norms. Many medical studies of intersex people explicitly identify gender identity issues and non-heterosexual behaviours as being reasons for medical treatment which modify genital appearances.

Medical protocol recommendations

We believe that current protocols are flawed, with lifelong impact, and do not take individual needs into account.

Our recommended principles for medical interventions are the following:

1. Medical intervention should not assume crisis in our difference, nor normalisation as a goal.
2. Medical, and in particular surgical, interventions must have a clear ethical basis, supported by evidence of long term benefit.
3. Data must be recorded on intersex births, assignments of sex of rearing, and of surgical interventions.

4. Medical interventions should not be based on psychosocial adjustment or genital appearance.
5. Medical intervention should be deferred wherever possible until the patient is able to freely give full and informed consent; this is known as “Gillick competence”.
6. Necessary medical intervention on minors should preserve the potential for different life paths and identities until the patient is old enough to consent.
7. The framework for medical intervention should not infantilise intersex, failing to recognise that we become adults, or that we have health needs as adults.
8. The framework for medical intervention must not pathologise intersex through the use of stigmatising language.
9. Medical protocols must mandate continual dialogue with intersex organisations.

These principles lead us to support a focus on family counselling, rather than surgical intervention; the majority of these principles are supported by the Swiss National Advisory Commission on Biomedical Ethics.

Further, we seek a review of terminations on the basis of intersex differences, and a review of the use of off-label use of dexamethasone.

Legal recommendations

We wish to live in a society where we are not obliged to conform to binary sex and gender expectations, where our biological distinctiveness is not treated as if it’s 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. We wish to live in a society where our sex assignments are mutable, and not problematized, and where we (and others) can choose to remain silent on the matter of our sex, through an “unspecified” sex classification.

We seek recognition that our treatment by the medical profession and by the state is a human rights issue. We seek explicit inclusion in human rights and anti-discrimination legislation on the basis of our biological distinctiveness, without our having to submit either to medical intervention, nor a requirement that we “genuinely” identify as one gender or another.

Community support recommendations

Finally, the intersex community is one that currently falls in between the gaps. The intersex community is neither a disability community, nor an “LGBT” community. Our issues are not addressed by gay and lesbian, or “LGBT” health or disability organisations, even while we recognise that the National LGBTI Health Alliance is inclusive and has taken an umbrella role across distinct communities that includes intersex issues.

No intersex organisations in Australia have funding, whether to provide services to our community, or to liaise with government and/or health services. No intersex organisations in Australia employ staff. We subsist on volunteer time and minimal, gifted resources.

We hope that this resourcing issue might also be addressed by the senate and government.

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