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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

30 June 2013

1. Background

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.

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.

This further submission to the Senate inquiry into the involuntary or coerced sterilisation of people with disabilities is occasioned by several recent developments:

- A submission dated 27 June by the Australasian Paediatric Endocrine Group (APEG)¹
- Publication of press reports in The Age on 20 June (appended).
- Publication of a new intersex-inclusive policy document by the Council of the European Union on 24 June and intersex inclusion in efforts by the US National Institutes of Health (NIH).

These developments have placed new information into the public domain, and this is our first opportunity to reflect and comment.

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¹ Submission of the Australasian Paediatric Endocrine Group 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

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3. Contrasting rationales and evidence for surgical and hormonal intervention in Australia

We note from the Australasian Paediatric Endocrine Group (APEG) submission that surgery still takes place in Australia for the following:

- a. Surgery for cancer risk...
- b. Surgery for dysfunctional urine flow...
- c. Surgery for creation of a vagina...

Surgery may be performed to create a vagina where there was none present at birth. This surgery also involves separating the labial/scrotal folds which may be fused together, but no removal of tissue.

- d. Reconstructive reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis

The purpose of these procedures is for functional reasons such as to allow a male individual to urinate while standing, and 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. Surgery for psychosocial indications remains in contention both within Australasia and internationally, particularly for reduction of an enlarged clitoris, as tissue is being removed which the individual may wish was not removed later on.

Recognition of the contentious nature of these surgeries is absent from public statements by Professor Sonia Grover of the Royal Children's Hospital, Melbourne. Professor Grover is part of the hospital's specialist team working with intersex patients and families, alongside two of the four authors of the APEG submission, Professor Garry Warne and Dr Jacqueline Hewitt.

On 20 June *The Age* reported a view – and a direct quote – by Professor Grover demonstrating absolute medical certainty:

The Royal Children's Hospital Melbourne currently performs one or two gonadectomies a year on infants with undescended testes... The hospital also performs 10 to 15 genital reconstruction operations a year often on girls under the age of two.

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.⁸

In contrast, APEG suggests that there is conflicting evidence on outcomes with "particular concern" around sexual function. The group gives the following recognition of the limited evidence for surgical intervention:

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. Surgical techniques have differed over time, with clitorectomy no longer performed, and clitoral reduction now being favoured by surgeons.... there is a lack of strong evidence to either support or refute specific recommendations on timing.

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The profoundly conflicting opinions provided by different members of the same specialist team at the Royal Children's Hospital are a matter of deep concern to us.

We take the phrasing around "conflicting results" ... "*with particular concern regarding sexual function and sensation*" to confirm what we have seen reported in Schützmann² and elsewhere (detailed in our second submission), that such outcomes are poor. With surgical rationales that are intrinsically focused on genital appearance, this is completely unsurprising. Properly informed consent should fully reflect these "*conflicting results*" and "*particular concern*", not an assertion of certainty.

We note that hormonal interventions are also made:

For girls with a specific diagnosis of congenital adrenal hyperplasia there can be spontaneous reduction in the size of the clitoris with adequate hormone replacement therapy

We are concerned at the implications of iatrogenic (medically induced) changes on puberty and future gender identity. We believe that the problematisation of physical sex-related non-conformity is itself the problem.

The APEG concludes:

4. APEG recognises that there are ongoing difficult decisions regarding genital surgery in minors with DSD raised female, specifically regarding reduction in size of the clitoris/phallus i.e., at what degree of ambiguity is surgery indicated and when is the best time to perform such procedures? It will not be possible to legislate on this matter

We don't believe that the available evidence supports this. Clitoris/phallus size is irrelevant to most people's childhood, as it should be. Personal autonomy is recognised in legislation on female genital mutilation. We believe it should be recognised here; we believe that it is possible to legislate on this matter.

Given the paucity of evidence, and the limiting, life-changing nature of surgical and hormonal interventions, we submit that they must be discontinued.

In our third submission, we drew the Inquiry's attention to the foundational study in this area, by Dr John Money, and pointed out that infant genital surgeries have been contentious now for many years. We still lack sound, clear evidence of both necessity and good outcomes, and we lack longitudinal or control studies. Clinical practice is still based on inconsistent assertions of psychosocial risks and benefits, and cancer risk.

4. Timing of surgery

We welcome the acknowledgement of contention by APEG in relation to infant genital surgery that:

APEG acknowledges the contention in this area, and recommends that until further evidence becomes available, surgery for the purposes of appearance should only occur if consistent with international medical guidelines on severity of disorder, and that in terms of timing, parents should be thoroughly counselled about the options of very early surgery, delay until later in infancy or delay until the child can be involved themselves in the decision to operate. We are in the process of performing a study of the recommendations on surgical timing across the clinicians in our organisation.

² 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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We are glad that the Group is finally studying recommendations on surgical timing; the lack of data or consistency on this issue is itself a matter of concern showing a lack of adequate regulation and guidelines. We fear that the continued lack of data represents a lack of will and oversight, rather than a lack of clinical resources.

We contend the value of “international medical guidelines” when those guidelines are the subject of increasing international concern. We note that international best practice, defined in a report of the Swiss National Advisory Commission on Biomedical Ethics, does not support early surgeries.

We note a conflict in expectation between APEG and a parent’s group. APEG recommend:

APEG recommend that treatment be consistent with international practice guidelines as well as ethical principles, with all decisions made with the full informed consent of the parents and the assent of the young person if they are old enough to be able to become involved in decision making.

Yet *The Age* reports comments by a parent (not a person with CAH, but president of a parent group related to CAH):

*Michelle Hoare, president of the Congenital Adrenal Hyperplasia Support Group of Australia, says: "You don't want your child to look different. That's one of parents' main concerns."*⁸

In practice this means that appearance-related surgery, for social reasons with contentious, limited evidence will continue unless governments intervene.

In a closely related issue not addressed by APEG or Professor Grover, Furtado et al found that intersex people were likely to change lived sex in 8.5-40% of cases, depending on diagnosis³. This is also the case with CAH (Congenital Adrenal Hyperplasia), which was the subject of Professor Grover’s statements to *The Age*. These figures are astonishingly high and remain current concerns. Also in *The Age*:

*Andie Hider, vice-president and medical liaison representative for the Androgen Insensitivity Support Group of Australia knows a couple "torn apart by grief because of a wrong decision [about gender] made when the child was young".*⁸

In our view, it is not reasonable to dismiss such cases 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.

Deferring surgery until such time as a patient can personally give fully informed consent would prevent or substantially reduce the number of incorrect surgical assignments.

We commend the Swiss National Advisory Commission on Biomedical Ethics (tabled to the Senate Inquiry) when it recommends that appearance-related surgery should be deferred until a patient can give such consent, with criminal sanction.

In common with several disability groups who have made submissions to this Inquiry, we do not believe that the court system is well placed to adjudicate in these matters.

³ Furtado, P. S. et al., 9 October 2012, *Gender dysphoria associated with disorders of sex development*, in *Nat. Rev. Urol.* doi:10.1038/nrurol.2012.182, <http://www.nature.com/nrurol/journal/vaop/ncurrent/abs/nrurol.2012.182.html>, accessed 2 March 2013

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5. Gonadectomies and CAIS

We note with thanks the comments by APEG regarding our statements on gonadectomies in the case of intersex people with Complete Androgen Insufficiency Syndrome (CAIS):

We are concerned that some of the information presented appears to have been either misunderstood, or misrepresented in error, leading to inaccurate conclusions. Some authors have misunderstood the difference between high-risk and low-risk cancer groups within DSD, and in particular, one submission incorrectly implied that the cancer risk for a diagnosis in the highest-risk group ("PAIS with non-scrotal/intra-abdominal testes") was quoted by Warne and Hewitt as being the cancer risk for a diagnosis in the low-risk group ("CAIS"), as outlined in Table 2. The implication is that testes or ovaries are being removed from patients with diagnoses at low-risk of cancer, such as CAIS, however this is incorrect. The recommendation of Warne and Hewitt, and in the current medical literature, is for preventative surgical removal only in the high-risk and intermediate-risk cancer group...

In our first submission we quoted from a publicly available document entitled "*Disorders of sex development: current understanding and continuing controversy*" written by two of the authors of the APEG submission and published in the Medical Journal of Australia⁴. That document recommended

a "risk management strategy be prepared for each patient ... which would mandate ... removing all intra-abdominal gonads that cannot be brought down into the scrotum".

The breadth of subject matter in the short document makes it hard to identify, on the basis of the APEG interpretation, whether this risk management strategy applies to all patients with testes or XY chromosomes, or just those with male-sex rearing (i.e. not including CAIS).

Nevertheless, the Inquiry heard personal testimony from Australians with CAIS who have been subjected to gonadectomies in Australia on the putative basis of a cancer risk. If the APEG is now claiming that it is incorrect to state that "*testes or ovaries are being removed from patients with diagnoses at low-risk of cancer, such as CAIS*" then it is not clear when this policy change has occurred or, indeed, whether it is universally applied in Australia.

Further, removal of gonads in CAIS is an international norm, and one often portrayed in the international media as a way of "saving" affected parties. Professor Georgiann Davis wrote on this subject in May this year:

Less than a week ago, the world was introduced to Susie, the dog who was allegedly "saved" when her veterinarian surgically erased her intersex trait. Intersex traits involve being born with either internal and/or external ambiguous genitalia.

The veterinary office that operated on Susie informed her human guardian that they needed to surgically remove her internal testes because, "If they had been left in, the testicles would have turned cancerous." My parents were told something similar when I was diagnosed [with CAIS], despite the fact that an intersex trait, especially CAIS, rarely poses a health threat. Still, the intersex trait was erased from our respective bodies...⁵

⁴ Garry Warne and Jacqueline Hewitt, *Disorders of sex development: current understanding and continuing controversy*, in Medical Journal of Australia, <https://www.mja.com.au/journal/2009/190/11/disorders-sex-development-current-understanding-and-continuing-controversy> accessed 1 January 2013.

⁵ Georgiann Davis, *Standing with Susie the Dachshund* in Ms Magazine, <http://msmagazine.com/blog/2013/05/09/standing-with-susie-the-dachshund/>, accessed 11 May 2013.

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It remains international practice, today. Nakhal et al, writing in *Radiology* Volume 268, July 2013 (we have a pre-publication copy) reports on the UK experience:

*Traditional management of CAIS includes gonadectomy with subsequent hormonal replacement... Current practice is to perform gonadectomy in late adolescence after completion of spontaneous pubertal development.*⁶

The APEG suggests that:

APEG recommends that ... the definition of 'therapeutic' treatment should be that which is defined as such by the current medical literature.

This really seems to be an argument for whatever the specific surgeon or team prefers it to be. We submit that conformity with "international medical guidelines" in Australia is likely to be inconsistent with the stated goals of APEG, and should not be relied upon by the Inquiry as evidence of good practice.

We warmly welcome the acknowledgement that testes in CAIS represent a low risk, and the consequential rejection, by APEG, of unnecessary gonadectomies in people with CAIS. We believe that it would be consistent with this approach to end appearance-related genital surgeries and hormonal intervention on intersex infants and children.

6. Intersex and DSD

We regret the statement in the Australasian Paediatric Endocrine Group submission that the term "intersex" is found to be pejorative and offensive by unspecified "other patient groups in Australia". We believe that this is overstated. The Inquiry received testimony in March from representatives of multiple organisations that use the term in response to the wishes of their open memberships of affected individuals.

We recognize that different viewpoints are unsurprising, given strongly different medical and community perspectives on treatment protocols. Such differences are evident with other minorities, such as people with disabilities, and also lesbians, gay men and trans people who prefer to use alternative terms. Some overseas groups refer to "Differences (not Disorders) of Sex Development", or "Intersex/Differences of Sex Development"⁷. We find intersex to be a simple term, relatively widely understood, and the best available.

Pejorative associations are, in our view, a reflection of stigmatization. Stigmatisation is best addressed, in our view, by improving social awareness, acceptance of difference, and tackling discrimination. The persistence of stigma is recognized even amongst clinicians who favour "Disorder of Sex Development" or "DSD"; use of "DSD" does nothing to address that stigmatisation. Professor Sonia Grover of the Royal Children's Hospital, Melbourne was quoted on 20 June in *The Age*:

Indeed, while there are people with intersex conditions on company boards, winning Olympic medals and contributing at every level of society, there is still a stigma surrounding the condition and most intersex prefer not to disclose that they have it. Professor Grover confirms that stigmatisation is still a big problem.

⁶ Nakhal, Hall-Craggs, Freeman, Kirkham, Conway, Arora, Woodhouse, Wood, Creighton, July 2013, *Evaluation of Retained Testes in Adolescent Girls and Women with Complete Androgen Insensitivity Syndrome*, in *Radiology*, Volume 268: Number 1, doi 10.1148/radiol.13121068, accessed 26 June 2013.

⁷ Advocates for Informed Choice in the US is a good example of this, <http://aiclegal.org>

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"We would never have one of our patients [with a disorder of sex development] as the face of a Good Friday appeal because of the stigma associated with the diagnosis," she says.

"That's what does the damage. Shame and secrecy," says Mani Mitchell [director of Intersex Trust NZ and board member of Advocates for Informed Choice]⁸

The well publicized inclusion of intersex status in the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013 directly addresses that discrimination and stigmatisation. We thank Parliament for the decisive multi-partisan inclusion of intersex in anti-discrimination protection. The passing of the legislation has been the subject of much relief and joy.

The inclusion of intersex in this legislation received approval from intersex community organisations, and a broad spectrum of other human rights, legal, and special interest organisations, including tacit acceptance from some more mainstream religious groups like the Australian Association of Christian Schools⁹. This was recognized in both 2013 reports by Senate Inquiries on anti-discrimination legislation, that on the Human Rights and Anti-Discrimination Bill, and the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill.

The inclusion of intersex in terms that we would describe as accurate in the Attorney General's guidelines on recognition of sex and gender – guidelines that were the subject of public consultation this year before publication in June.

Finally, the use of "intersex conditions", rather than DSD, was the consensus finding in the Victorian Health Department's decision making guidelines, and this document benefitted from both clinical and community consultation, and acceptance of the terminology used.

We believe that clarity about the term intersex, and concerns about it being pejorative, are not the key reasons for the terminology shift. Professor Georgiann Davis, writing in the journal *Sociology of Diagnosis (Advances in Medical Sociology)* recounts the history behind the medical profession's shift from 'intersex' to 'DSD' thus:

By the 1990s, the medicalized treatment of intersexuality was heavily critiqued by intersex activists upset that they had been lied to about their medical condition, surgically modified in ways that left them with diminished sexual desire, minimal ability to reach sexual pleasure, and in some cases, an increased likelihood of incontinence. Intersex activists responded by protesting outside of pediatric medical association meetings accusing doctors of pediatric "mutilation." While their confrontational strategies were initially ignored by the medical profession, by the year 2000, the American Academy of Pediatrics (AAP) acknowledged that their historical treatment of intersexuality left their profession in a state of "social emergency".

...By the year 2000, Chase was delivering a plenary address to the Lawson Wilkins Pediatric Endocrine Society, a group she was once protesting against. This successful activist encroachment into medical turf was highly unusual for two overlapping reasons. It marked the first time an activist's perspective was solicited by organizers of a major medical conference. And, it was "the first time that the society's annual symposium was devoted to intersexuality".

⁸ 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.

⁹ Submission 30 to the Senate Inquiry on the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013.

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The intersex health and sterilisation issues before the Inquiry are not new issues. Davis concludes:

I argue this shift [to DSD] was a reaction to activist challenges to medical jurisdiction over intersexuality, and doctors' insistence on the DSD terminology was a reassertion of their medical authority"

The new DSD terminology constructs "sex" as a scientific phenomenon, and a binary one at that. Under such frame, intersex experts neatly link intersexuality to science, and thus are able to justify surgery. This places intersexuality neatly into medical turf and safely away from critics of its medicalization. At the same time, the connection to science increases medical credibility, which in light of intersex activism, is necessary.

...With the new DSD terminology, intersexuality has been returned to medical turf where medical professionals, notably surgeons, are able to reclaim authority over the intersex body...¹⁰

7. Intersex is now an international human rights issue

The continued assertion of intersex terminology by community organisations does not simply represent a rejection of unnecessary medicalisation and disordering for social reasons, it represents a focus on our human rights. We believe that surgical intervention, especially for "psychosocial" reasons, associated with stigma and familial or social distress, must be seen in a human rights context. Too often, intersex infants, children and adults fail to receive the same rights and treatment as that afforded to other infants, children and adults.

Intersex is not referenced only in Australian legislation and guidelines. Increasing global concern about the human rights implications of appearance-related genital surgeries on children mean that intersex is now referenced in international reports and agreements, albeit often imperfectly. Once such example is the report of the UN Special Rapporteur of Torture, referenced in our second submission.

Another example is a new European Union Foreign Policy Framework, "*Guidelines to Promote and Protect the Enjoyment of All Human Rights by Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Persons*" published by the Council of the European Union on 24 June¹¹. The document states:

2 ... LGBTI persons constitute a vulnerable group, who continue to be victims of persecution, discrimination, bullying and gross ill-treatment, often involving extreme forms of violence, including torture and murder. Discrimination against LGBTI persons is often rooted in societal norms and perceived roles that perpetuate gender inequalities.

Working definitions

The acronym LGBTI describes a diverse group of persons who do not conform to conventional or traditional notions of male and female gender roles. LGBTI people are also sometimes referred to as "sexual, gender and bodily minorities".

It offers a differently worded definition of intersex – but one that is entirely consistent with that in Australian legislation and the federal sex and gender recognition guidelines:

¹⁰ Georgiann Davis, 2011, *DSD is a Perfectly Fine Term: Reasserting medical authority through a shift in intersex terminology*, pp. 155-182 in McGann, PJ & David Hutson (eds) *Sociology of Diagnosis (Advances in Medical Sociology) Volume 12*. Emerald, UK, ISBN 978-0-85724-575-5. [http://dx.doi.org/10.1108/S1057-6290\(2011\)0000012012](http://dx.doi.org/10.1108/S1057-6290(2011)0000012012), accessed 1 May 2012.

¹¹ Council of the European Union, http://www.consilium.europa.eu/uedocs/cms_Data/docs/pressdata/EN/foraff/137584.pdf accessed 27 June 2013.

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... The term intersex covers bodily variations in regard to culturally established standards of maleness and femaleness, including variations at the level of chromosomes, gonads and genitals.

This development has been broadly welcomed, and recognised as a major step forward; indeed, recent Australian developments have been similarly regarded overseas.

We believe that the presumptions underlying the statements made by APEG reflect “societal norms and perceived roles that perpetuate gender inequalities” and the rigid application of societal sex norms that are unwarranted in their application to children. This is evidenced by its statement supporting:

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 rearing¹

The Council of the European Union document also states:

10.1 Do children suffer from discrimination as a result of sexual orientation or gender identity?

...Are children subjected to medically unnecessary surgery, performed without their informed consent, or that of their parents, in an attempt to ‘fix’ their sex?

This phrasing on “informed consent” and “fix’ their sex” echoes the words of the UN Special Rapporteur on Torture. Other examples include tabled testimony to the Inter-American Commission on Human Rights. In the US, the National Institutes of Health (NIH) is now starting to include intersex as “part of our efforts to advance the health of LGBTI individuals”¹².

We respectfully assert that appearance-related genital surgeries on infants are not medically necessary, and parents lack full information.

8. Data and long-term follow-up

Appearance-related genital surgeries on infants have been contentious for many years. In our third submission we tabled a human rights report from San Francisco in 2005, and evidence from the David Reimer case in 1997.

The APEG has now, in its submission to this Inquiry, called for funding to establish a “patient registry to ensure adequate follow-up of patients with DSD”, acknowledging significant gaps in their data on patient outcomes.

We are glad that APEG recognises the institutional failings in the absence of long term follow up of intersex people. We are deeply concerned that surgical interventions are justified without such follow-up and adequate evidence. We welcome the acknowledgement that there is no properly constituted multi-disciplinary team in Australia. We submit that the any such team must acknowledge and reflect community and human rights concerns as well as clinical perceptions of best practice.

Advocates for Informed Choice (AIC), in a statement to the US National Institutes of Health on 27 June state that significant gaps in intersex health data include psychological support for parents, families, and intersex children, youth and adults, and also:

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Health outcomes research looking at children with atypical genitals who did not have early genital surgery. We are unaware of any study in the last 50 years that specifically looks at intersex people who did not undergo early genital surgery.¹²

We concur. This gap is not identified in the APEG submission.

If the Inquiry determines that a registry would be helpful, we would add this and additional issues for analysis as part of such a project. The following two issues lie outside the scope of the terms of reference of this Inquiry, so we have been unable to comment on them in detail:

- policy and practice on the eugenic de-selection of intersex people through terminations of fetuses identified with "DSDs".
- investigate the use of prenatal dexamethasone to modify the appearance and behaviour of XX CAH infants raised as girls; we have received anonymous evidence that this is possible in Australia despite overseas evidence that it results in a failure to thrive by some infants subjected to this treatment prenatally.

While recognising commonalities due to attitudes towards sex and gender non-conformity, which includes bodily non-conformity, like AIC we also agree that intersex health issues need to be addressed by intersex-specific health goals and community organisations:

the primary issues in intersex... health are very different from those of the LGBT community. Research that simply looks at intersex as a kind of sub-category of LGBT will fail to capture the key concerns of our constituents.¹²

Our specific health priorities relate to the iatrogenic effects of surgical and hormonal treatment, the effects of shame and secrecy, psychological support for individuals, and support for the families of infants and children with intersex variations.

LGBT organisations lack the capacity or the engagement with an intersex community that largely does not identify as gay, lesbian, bisexual or transgender.

There are no funded intersex community organisations in Australia and, given recent legislation and guidelines and this Inquiry, we are currently operating considerably over capacity. The UN Special Rapporteur on Torture highlighted structural inequalities that result in damaging treatment; we believe that specific support for the intersex community sector is necessary to overcome this.

9. Conclusions

Intersex is becoming an issue of international concern from a human rights perspective, with increasing scrutiny of the role of the medical profession in surgically assigning sex to infants. We believe that surgical intervention, especially for "psychosocial" reasons, associated with stigma and familial or social distress, must be seen in a human rights context.

Clinicians have been aware of the contentious nature of appearance-related infant genital surgeries and hormonal intervention for many years, at least since the 1997 publication of new data on the David Reimer case. There is, in our view, no basis for the continued appearance-related intervention using such thin, inadequate data on outcomes. The persistent lack of data or consistency on surgical timing by clinicians within the Australasian Paediatric Endocrine Group is also a matter of concern. We fear that the continued lack of data represents a lack of will and oversight, rather than a lack of clinical resources.

¹² Advocates for Informed Choice, 27 June 2013, *The National Institutes of Health (NIH) Invites Intersex to the Table!* <http://aiclegal.org/the-national-institutes-of-health-nih-invites-intersex-to-the-table/> accessed 29 June 2013.

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Lack of data results in lack of support for children, adolescents and adults. Support for the intersex community sector is necessary to overcome structural inequalities and address intersex-specific health goals.

We warmly welcome the rejection, by APEG, of unnecessary gonadectomies in people with CAIS. We believe that it would be consistent with this approach to end appearance-related interventions on intersex infants. Such interventions should be deferred until patients can personally give fully informed consent – our core demand.

It is not clear that parents can give fully informed consent if they are not made fully aware of conflicting evidence regarding outcomes, and particular concern about sexual function and sensation. We agree with the Swiss National Advisory Commission on Biomedical Ethics when it recommends that appearance-related surgery should be deferred until a patient can consent, with criminal sanction.

In practice, parent demand and clinician support means that appearance-related surgery, for social reasons with contentious, limited evidence and no long-term follow-up will continue unless governments intervene.

Conformity with “international medical guidelines” should not be relied upon by the Inquiry as evidence of good medical practice.

We do not support the selective utilisation of international guidelines; we would support the establishment of national guidelines that ensure personal bodily autonomy on appearance-related issues.

In common with disability groups, we do not believe that the court system is well placed to adjudicate in these matters.

Suggested citation

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It takes more than two

June 20, 2013

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When they are born some people have not travelled the conventional biological path to being male or female. What happens then? Andrew Bock reports on being intersex.

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My life with Androgen Insensitivity Syndrome

Meet Christy North, who was born with Androgen Insensitivity Syndrome.

Call to end intersex genital operations

Given a choice between male and female on official documents, Tony Briffa ticks both boxes but prefers to tick neither. Briffa also prefers not be referred to as "he" or "she".

"I would honestly feel like I was lying if I filled out a document and I put one or the other," says Briffa, a former mayor of Hobson's Bay who has tried living as both a female and a male.



Christy North, now 34, was diagnosed with complete androgen insensitivity syndrome when she was aged two. *Photo: Ken Irwin*

Briffa was born with partial androgen insensitivity syndrome, one of more than 30 "intersex" conditions. The term refers to more than 30 different conditions characterised by having biological attributes of both sexes or attributes that are not wholly female or male. These may be chromosomal, hormonal or physical variations including ambiguous genitals.

"I was born both and I feel both," Briffa says. "And I fiercely want to be recognised in the gender I was born, which is both."

For the first six weeks of our lives we are arguably all intersex. Humans do not develop sexually distinct features until a series of genetic and hormonal catalysts begin their work in the seventh week of life in the womb. Individuals who do not travel the conventional biological path to maleness or femaleness develop intersex conditions, also known by doctors as disorders of sex development or DSD.

Sometimes known as hermaphrodites or androgynes, these permutations of male and female have been known to exist; people recognised that sexuality is more like a spectrum, or "an overlapping pair of bell curves", than a binary set of two genders.

Medical studies estimate between one in 250 babies are born with one of the milder intersex conditions and one in 4500 births for rarer conditions. This means intersex conditions are more common than Down syndrome. International studies show over 1 per cent of all babies have some kind of intersex condition.

"Society is happy with the idea that this kind of variability around sex is incredibly rare," says Gina Wilson, president of advocacy group Organisation Intersex International. "We're saying it's more common than being redhead."

Over the past century differences of sex development were hidden from the public and hospitals hid diagnoses from parents. Surgeons performed genital surgery entailing sterilisation and lifelong hormone treatment to assign infants one gender or the other, often with the consent of poorly informed parents. Sometimes the surgeons got the gender assignment wrong.

The use of surgery to change the sexual anatomy of children was promoted during the 1950s and 1960s by the controversial New Zealand-born sexologist and paediatrician, Professor John Money.

Money had his own - now disputed - theories about how sexual identity developed.

Based at John Hopkins University in Baltimore, he argued that social and environmental cues interacted with a child's genes and hormones to shape whether the person identified as male or female. He said early assignment of gender with medical reinforcement would help a child grow up happily in one gender.

Medical diagnoses and treatments have improved dramatically in Australia in the past 20 years.

These days fewer gender assignment or genital enhancement operations are done on children than 10 years ago.

The Royal Children's Hospital Melbourne currently performs one or two gonadectomies a year on infants with undescended testes. According to medical studies, in certain cases undescended testes have a 50 per cent chance of becoming cancerous, although some intersex groups point to studies that show lower risk and dissatisfaction with surgery.

The hospital also performs 10 to 15 genital reconstruction operations a year often on girls under the age of two. Genital surgery is conducted mostly on infants with female chromosomes and congenital adrenal hyperplasia, a condition that causes some girls to have more masculine-looking genitals. Surgery is conducted on female infants to open or enlarge vaginal openings or to reduce or reshape clitorises.



Former Hobsons Bay mayor Tony Briffa. *Photo: Scott McNaughton*

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.

She says genital surgery can be compared to widely accepted cosmetic surgery to correct such things as a cleft lip and palate.

But when it comes to surgery older people with intersex conditions often suffered because of social and medical attitudes of the time.

"Trace" was born in rural Victoria with Klinefelter syndrome (which gave her one extra X chromosome than the usual male) and non-conforming genitalia. Like other older intersex people, her early medical records have gone missing, but four operations as a child left her without any genitalia.

"It was never explained to my mother. She was told I had a condition and that I would never have a child and it would be best for me to have operations 'to clean up downstairs'," Trace says.

Trace was raised as a boy but her father, a Jehovah's Witness, physically abused her. She was eventually made a ward of the state but placed in a girls' home while she went to school as a boy. She refused to attend sports classes, preferring to be punished than having to undress in front of others in changing rooms.

She was placed on male hormones but later began to question her gender and stopped taking the hormones. In her 20s she became confused about her gender identity and eventually decided to adopt a female identity and name.

"If there was choice in life I certainly would have lived androgynously but society was so gender-driven in early days."

Trace, now a successful business person, counts herself lucky because "many older intersex people don't manage to fight off poverty and depression and some take their own lives".

Every intersex condition has different physical manifestations and requires different management. Women with complete androgen insensitive syndrome (CAIS) are often tall and striking looking with slightly masculine or angular features and ageless skin. Some well-known actresses, models and athletes are known to have the condition.

Christy North, now 34, was diagnosed with CAIS when she was two and had internal, "non-functioning" testes surgically removed. At 12, she found out she wouldn't menstruate or be able to have children. She was also put on a lifelong oestrogen replacement course.

Hospitals no longer remove the testes of women with CAIS but North is not unhappy that hers were.

"I am more than happy to be female. I don't have a choice. I was born a female. I am XY. But I can't become male. I have female parts. Just not the internal makings of a female.

"In 20 years they will know what happens when you take HRT for 50 years. We also don't know what would happen if I stopped taking it. I just think what I do now could help those in the future. I don't want to see myself as a guinea pig, but I guess I can be."

Parents face extremely difficult decisions about what treatments they allow their child to have soon after being told their baby has an intersex condition.

Andie Hider, vice-president and medical liaison representative for the Androgen Insensitivity Support Group of Australia knows a couple "torn apart by grief because of a wrong decision [about gender] made when the child was young".

Michelle Hoare, president of the Congenital Adrenal Hyperplasia Support Group of Australia, says: "You don't want your child to look different. That's one of parents' main concerns."

She poses the question: "Would you terminate a child that has abnormal genitals?"

The Australian president of Organisation Intersex International, Gina Wilson, is concerned that prenatal screening and ultrasounds may be leading to an increasing number of terminations of fetuses with intersex conditions.

Anne, a parents' representative for AISSGA, whose daughter has CAIS, says "You think it is the end of the world when you first find out and then you find out they can still lead a happy fulfilling life regardless."

Indeed, while there are people with intersex conditions on company boards, winning Olympic medals and contributing at every level of society, there is still a stigma surrounding the condition and most intersex prefer not to disclose that they have it.

Professor Grover confirms that stigmatisation is still a big problem.

"We would never have one of our patients [with a disorder of sex development] as the face of a Good Friday appeal because of the stigma associated with the diagnosis," she says.

"That's what does the damage. Shame and secrecy," says Mani Mitchell, president of OII New Zealand.

"If we are going to change anything it is to help parents be comfortable with a child who is different. Helping parents find a different language to talk to their kids."

Mitchell says society advocates acceptance of racial difference but has trouble accepting sexual difference. "We don't deal with racism by turning everybody brown."

Advocacy groups believe the continuing use of the medical term "disorder of sex development" perpetuates stigma and helps persuade parents their child has a problem that needs to be fixed.

The federal government is taking steps to help reduce this stigma. From July 1, the new federal Guidelines on the Recognition of Sex and Gender will allow Australians to tick a third box, the "X" box, denoting "Indeterminate/Intersex/Unspecified" on all government documents, including passports.

Also The Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013, which is expected to be passed by the Senate this week, will give intersex people legal protection against discrimination for the first time in Australia.

But Andie Hider says governments need to go further. "Do we really need to have male or female on a driver's licence or a birth certificate?"

Indeed, some intersex people see debates about subjects such as different and same-sex marriage as absurd. "Every relationship I have is going to be part heterosexual and part same-sex." Briffa jokes: "Maybe I can marry myself."

Andrew Bock is a Melbourne journalist.

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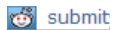
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My life with Androgen Insensitivity Syndrome
Meet Christy North, who was born with Androgen Insensitivity Syndrome.

● **Focus: It takes more than two**

Advocacy groups have called for an end to genital surgery on infants with intersex conditions, saying many operations are not medically necessary and are performed to reinforce a particular gender.

"No genital surgery is life-preserving," says Gina Wilson, president of Organisation Intersex International in Australia. "It's cosmetic and normalising."



In a submission to a recent Senate inquiry the organisation compared such surgery to 'infant genital mutilation'.

In a submission to a recent Senate inquiry the organisation compared such surgery to "infant genital mutilation".

Ms Wilson said surgeons should wait until a child reached an age of informed consent. The term intersex refers to people with genetic, hormonal or genital features that are not completely male or female, or a mixture of both.

Andie Hider, vice-president and medical liaison representative for the Androgen Insensitivity Syndrome Support Group of Australia, said: "Unless there is significant impairment that will cause ongoing health concerns until it is rectified, I don't think there is a justifiable reason to operate."

The group, which represents one category of intersex conditions, has called for a moratorium on non-urgent medical intervention. The calls come as new federal government guidelines that allow Australians to tick a third box, the "X" box, signifying "indeterminate/intersex/unspecified" on all government documents and passports, take effect on July 1.

The Senate this week is also expected to pass the the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013, giving intersex people legal protection against discrimination for the first time in Australia.

Medical studies estimate there are between one in 250 births for milder intersex conditions, to one in 4500 births for rarer conditions. This means intersex conditions are more common than Down syndrome.

Melbourne's Royal Children's Hospital performs one or two gonadectomies a year on infants with undescended testes. It also performs 10 to 15 genital reconstruction operations a year, often on girls under the age of two.

Ms Wilson points to several studies showing dissatisfaction among people with congenital adrenal hyperplasia who had surgery as infants.

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