

June 2018

Shadow Report submission: Australia

This Report is by **Intersex Human Rights Australia (IHRA)**, a national organisation run by and for people born with intersex variations. Formerly known as Organisation Intersex International Australia, IHRA is a not-for-profit company, with charitable status. The submission was written by co-executive director Morgan Carpenter, M.Bioeth. (Sydney), with input from the board and members of IHRA. Contact morgan.carpenter@ihra.org.au

1 Summary

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) seeks to eliminate discrimination against women, and eliminate prejudices and customary practices based on gender stereotypes.¹ Joint CEDAW and CRC General Comment 31 calls for the elimination of harmful practices.²

A pattern of human rights abuses on infants, children and adolescents born with intersex traits occurs in Australia, without effective, independent oversight, often based on gender stereotypes, and lacking a scientific basis. Evidence includes the 2016 Family Court of Australia case *Re: Carla (Medical procedure)* which facilitated the unnecessary sterilisation of a 5-year old child. Incidental disclosure in that child's medical history of a clitorrectomy and labioplasty was described by the judge as follows:

Surgery already performed on Carla has enhanced the appearance of her female genitalia³ (at [2])

In 2014, Carla underwent two operations. In March that year, Dr B, performed a 'clitoral' recession and labioplasty to feminise Carla's external appearance. (at [16])

¹ United Nations. Convention on the Elimination of All Forms of Discrimination against Women. 1981. <http://www.ohchr.org/Documents/ProfessionalInterest/cedaw.pdf>.

² CEDAW, CRC. Joint general recommendation No. 31 of the CEDAW/general comment No. 18 of the CRC on harmful practices. 2014. Report: CEDAW/C/GC/31-CRC/C/GC/18.

³ Family Court of Australia. *Re: Carla (Medical procedure)* [2016] FamCA 7. <http://www.austlii.edu.au/cgi-bin/sinodisp/au/cases/cth/FamCA/2016/7.html>

Harmful practices occur despite rhetoric by Australian governments that denies or asserts changes to clinical practices, and that asserts recognition and valuing of intersex people.⁴

A 2013 Senate committee inquiry made recommendations for change to clinical practice. The Australian government has rejected those recommendations; federal and State governments have failed to act. The Family Court has been unable to perform an independent role sought by the Senate inquiry. A 2017 intersex community consensus statement defines a set of demands, the *Darlington Statement*, in response.⁵

We urge the Committee to make strong recommendations in line with its prior recommendations,⁶ and those of other Treaty Bodies.

2 Recommendations

We respectfully request that the Committee asks the government of Australia to:

1. Guarantee bodily integrity, autonomy and self-determination to children born with non-normative sex characteristics, and ensure that no-one is subjected to medically unnecessary medical or surgical treatment during infancy or childhood.⁷
2. Prohibit unnecessary deferrable surgical or other medical treatment on intersex children until they reach an age at which they can provide their free, prior and informed consent.⁸ For example, by criminalising deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal informed consent by the recipient.
3. Provide redress and access to justice to people who have undergone unwanted medical interventions to “normalise” sex characteristics.⁹
4. Commit to development, with meaningful community participation, of appropriate, transparent, human rights-based standards of care for treatment of persons born with sex characteristics that do not fit norms for female or male bodies.¹⁰
5. Ensure that all necessary medical interventions to modify the sex characteristics of children with intersex variations are subject to oversight, for example, *post facto* oversight, to ensure compliance with human rights norms.
6. Ensure that medical and psychological professionals, and parents, are educated on bodily and sexual diversity, on human rights norms, and on the consequences of unnecessary interventions for children born with non-normative sex characteristics.¹¹

⁴ Carpenter M. The human rights of intersex people: addressing harmful practices and rhetoric of change. *Reproductive Health Matters*. 2016;24(47):74–84.

⁵ AISSGA, ITANZ, IHRA, Black E, Bond K, Briffa T, et al. *Darlington Statement*. 2017.

<https://darlington.org.au/statement>

⁶ CEDAW, Concluding Observations on Germany, CEDAW/C/CHE/CO/7-8, 2017, para 24(6).

⁷ Similar wording in CRC/C/NZL/CO/5, 2016, para 25, and CRC/C/ZAF/CO/2, 2016, paras. 39 to 40.

⁸ Similar wording in CEDAW/C/CHE/CO/7-8, 2017, para 24(d).

⁹ Similar recommendations in CEDAW/C/CHE/CO/7-8, 2017, para 24(6).

¹⁰ Similar relevant recommendations in CRC/C/NZL/CO/5, 2016, para 25; and CEDAW/C/FRA/CO/7-8, 2016, para 19(f).

¹¹ Similar wording in CAT/C/DEU/CO/5, 2011, and CRC/C/IRL/CO/3-4, 2016, para 40.

7. Ensure that adults with intersex variations are able to freely access medical interventions to manage sex characteristics, including unwanted iatrogenic (medically induced) changes to sex characteristics.

3 Intersex people

IHRA defines intersex people in line with a 2016 statement by human rights experts, published by the OHCHR:

Intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit the typical definitions for male or female bodies.¹²

We acknowledge the diversity of intersex people in our identities, legal sexes assigned at birth, genders, gender identities, and the words we use to describe our bodies. At least 40 different intersex variations are known,¹³ most genetically determined. Clinicians frequently use a stigmatising label, “Disorders of Sex Development” (“DSD”), referring to intersex variations.

4 Human rights framework

The joint CEDAW/CRC General Comment on harmful practices recognises “sex- and gender-based attitudes and stereotypes, power imbalances, inequalities and discrimination perpetuate the widespread existence of practices that often involve violence or coercion... justified by invoking sociocultural and religious customs and values” and misconceptions.² Further:

many women and children increasingly undergo medical treatment and/or plastic surgery to comply with social norms of the body, rather than for medical or health reasons²

The General Comment remarks on “legal provisions that justify, allow or lead to harmful practices” and lack of adequate or effective scrutiny by State and judicial bodies.² These issues are evident in treatment of intersex children.

In 2017, the UN Human Rights Committee responded to concerns regarding practices in Australia, concluding the government should:

26. ...move to end irreversible medical treatment, especially surgery, of intersex infants and children, who are not yet able to provide fully informed

¹² OHCHR, et al. End violence and harmful medical practices on intersex children and adults, UN and regional experts urge. 2016.

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>

¹³ Hiort O. I-03 DSDnet: Formation of an open world-wide network on DSD at clinician conference, “4th I-DSD Symposium”. 2013. http://www.gla.ac.uk/media/media_279274_en.pdf

*and free consent, unless such procedures constitute an absolute medical necessity*¹⁴

5 Australian policy context

5.1 Senate inquiry

In 2013, the Senate held a committee inquiry into the involuntary or coerced sterilisation of people with disabilities, and of intersex people.¹⁵ The inquiry process documented medical practices, including a public submission by the Australasian Paediatric Endocrine Group (APEG). That submission suggested there are clear indications for surgeries:

*Indications for surgery in DSD involve management of high cancer risk in the testes or ovaries, management of dysfunctional urine flow, creation of a vagina, or surgery for the purpose of appearance including reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis.*¹⁶

Management of high cancer risks and urinary issues should not be controversial. However, these issues are intertwined with non-therapeutic rationales for treatment. The Senate Committee was itself 'disturbed' by entwinement of different rationales in clinical reports.¹⁵

Regarding "Reconstructive reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis", APEG states that:

*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.*¹⁶

These are cultural, not functional, requirements for cosmetic interventions. Subsequent to such interventions APEG notes:

*particular concern regarding sexual function and sensation*¹⁶

¹⁴ Human Rights Committee. CCPR/C/AUS/CO/6.

¹⁵ Senate Community Affairs References Committee. Involuntary or coerced sterilisation of intersex people in Australia. 2013.

http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index

¹⁶ Australasian Paediatric Endocrine Group, Hewitt J, Warne G, Hofman P, Cotterill A. Regarding the Management of Children with Disorders of Sex Development. 2013.

<http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>

Beliefs underpinning medical interventions lack evidence and clear indications. For example, reflecting an earlier 2006 statement, a 2016 clinical review states:

*There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low ... There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.*¹⁷

In 2017, the Committee on Bioethics of the Council of Europe reported that no clinically-accepted standard of care:

*has emerged to explain, as a matter of science, how infant surgery will be certain to coincide with the child's actual identity, sexual interests, and desires for bodily appearance*¹⁸

In its 2013 report, the Senate committee found that:

there is no medical consensus around the conduct of normalising surgery...

Normalising appearance goes hand in hand with the stigmatisation of difference...

*There is frequent reference to 'psychosocial' reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child's avoidance of harassment or teasing, and the child's body self-image, there is great danger of this being a circular argument that avoids the central issues. Those issues include reducing parental anxiety, and ensuring social awareness and acceptance of diversity such as intersex. Surgery is unlikely to be an appropriate response to these kinds of issues.*¹⁵

The Senate report called for protocols and guidelines consistent with recommendations by IHRA (then named Organisation Intersex International Australia):

*3.129 The proposals put forward by Organisation Intersex International have merit, and are consistent with the committee's conclusions. The committee believes that a protocol covering 'normalising' surgery should be developed, and then adhered to in all cases of intersex children. Such a guideline should be consistent with Organisational Intersex International's recommendations*¹⁵

¹⁷ Lee PA, Nordenström A, Houk CP, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. *Hormone Research in Paediatrics*. 2016;85(3):158–180.

¹⁸ Zillén K, Garland J, Slokenberga S. 'The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties'. 2017.

Responding to the Senate inquiry, the federal government stated “the substantive regulation of medical treatment is a matter for state and territory governments”.¹⁹ No Australian government has implemented the Senate committee recommendations.

5.2 Flawed principles

A 2010 framework for the treatment of intersex children was developed in Melbourne, Australia.²⁰ It claimed that psychosocial risks that can be minimised through medical intervention include:

- *Risk that child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding with associated negative consequences*
- *Risk of social or cultural disadvantage to child, for example, reduced opportunities for marriage or intimate relationships²⁰*

The mention of marriage prospects is highly unusual, demonstrating similarity between rationales for intersex genital surgeries and rationales favouring FGM in countries where that practice remains a norm. As marriage in Australia excluded same-sex couples until December 2017, such rationales also promote a heterosexual ideal. The paper was criticised by some clinicians at the time, for example as:

*responding to the major DSD debate of a decade ago, namely over genital surgeries in infancy...
The authors have opted to ignore the existing DSD ethics literature in an effort to arrive at principles putatively unburdened by previous ethical engagement.²¹*

In 2013, a derivative framework was published by the State of Victoria, with limited community input.²² Yet a Victorian Department currently (May 2018) states:

*Potential for cosmetic surgical correction of **ambiguous genitalia** for virilised[sic] females should be discussed with the endocrinologist. Most surgical correction is now delayed until 6 months of age or later.²³*

That Department’s current (May 2018) page on congenital adrenal hyperplasia (CAH) states:

¹⁹ Attorney General’s Department. Australian Government response to the Senate Community Affairs References Committee reports on involuntary or coerced sterilisation. 2015.

²⁰ Gillam LH, Hewitt JK, Warne GL. Ethical Principles for the Management of Infants with Disorders of Sex Development. *Hormone Research in Paediatrics*. 2010;74(6):412–8.

²¹ Dreger A, Sandberg DE, Feder EK. From Principles to Process in Disorders of Sex Development Care. *Hormone Research in Paediatrics*. 2010;74(6):419–20.

²² Department of Health. Decision-making principles for the care of infants, children and adolescents with intersex conditions. 2013.

²³ Department of Health & Human Services. Congenital adrenal hyperplasia (CAH) in neonates. <https://www2.health.vic.gov.au:443/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-e handbook/conditions/congenital-adrenal-hyperplasia>

Girls with CAH may need surgery to reduce the size of the clitoris to normal, separate the fused labia and enlarge the vaginal entrance. The technical name for this operation is 'clitoral recession or reduction and vaginoplasty'. It is done either in one or two stages.

The clitoral reduction or recession is done in the first few months of life. The vaginoplasty is sometimes done at the same time as the clitoral reduction, but may be left until adolescence²⁴

Thus 2013 Victorian guidelines have not been binding on the State or its hospitals, have been disregarded in subsequent policy, and do not protect children's rights. Nevertheless, they were commended in the federal government response to the Senate report.¹⁹

Further, as the Senate report noted:

3.98 One of the difficulties that is seldom discussed is how to establish what constitutes 'normal', particularly in relation to what genitals 'should' look like. OII expressed concern about 'the absence of standard objective measures for cosmetic perceptions of "normal" female genitals'...

3.100 What little research exists regarding 'adequate' or 'normal' genitals, particularly for women, raises some disturbing questions ... The committee received no information indicating whether or not this natural variation in genital size and shape is taken account of ...or how medical specialists learn about the diversity of appearance of genitals or how they define 'normal' in their clinical practice.¹⁵

5.3 Data on rights violations

Lack of transparency underpins practices that violate children's human rights. Little statistical information is available.

The Royal Children's Hospital Melbourne reported to the media in 2013 that it performs 10-15 "genital reconstruction operations a year often on girls under the age of two".²⁵

Some data from the Australian Institute of Health and Welfare (AIHW) is available,²⁶ including for "vulvoplasties", defined as "any surgery performed on the outside female genital structures".²⁸ According to analysis of AIHW data²⁶ and a 2014 Department of Health review:

²⁴ Department of Health & Human Services. Congenital adrenal hyperplasia (CAH). 2014. <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/congenital-adrenal-hyperplasia-cah>

²⁵ Bock A. It takes more than two. The Age. 2013 Jun 20; <http://www.theage.com.au/national/it-takes-more-than-two-20130619-2oj8v.html>

²⁶ Carpenter M. The 'normalisation' of intersex bodies and 'othering' of intersex identities. In: Scherpe J, Dutta A, Helms T, editors. The Legal Status of Intersex Persons. 2018 (forthcoming).

- The Department found a “marked increase” of 105% in numbers of publicly-funded vulvoplasties in adolescents and adults between 2003/4 and 2012/13.²⁸ Numbers in 0-19 year age groups increased from 101 in 2002/3 to 258 in 2014/5.²⁷
- An average of 71.5 vulvoplasties were performed per year in children aged under 15 between 2002/3 and 2014/5; between 57-95 per year.²⁷
- There were 371 publicly-funded vulvoplasties for so-called “congenital malformations” between 2007/8 and 2011/2; averaging 74.2 per year.²⁸
- Additional surgeries take place under different categories such as “procedures for anomalies of genitalia”.²⁷
- There is no evidence of any overall reduction in numbers of surgeries relevant to minors with intersex variations between 2002/3 and 2014/5.²⁶

Exemptions in Australia regarding FGM do not apply to cosmetic interventions and the WHO recognises that medicalisation does not justify FGM, but clitorectomies, labioplasties and other vulvoplasties (including for aesthetic purposes) clearly happen.²⁹

The Australian framework on FGM shows profound confusion about intersex, appearing to describe intersex infants as “neither female or male” regardless of actual sex assignment, until surgically reinforced.³⁰ The FGM framework does not discuss necessity or evidence. Medical rationales, including parental distress, appearance “enhancement” and marriageability, mirror rationales evident for FGM in societies where FGM is the norm.

5.4 Darlington Statement

The *Darlington Statement* is a 2017 community consensus statement by Australian and New Zealand intersex organisations and advocates.⁵ Demands include:

- **“prohibition as a criminal act** of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent
- “mandatory independent access to funded counselling and peer support
- “appropriate **human rights- based, lifetime, intersex standards of care** with full and meaningful participation by intersex community representatives and human rights institutions

²⁷ Australian Institute of Health and Welfare. Procedures data cubes. 2017.

<http://www.aihw.gov.au/hospitals-data/procedures-data-cubes/>

²⁸ Department of Health. MBS Reviews Vulvoplasty Report. 2014.

[http://www.health.gov.au/internet/main/publishing.nsf/content/E393B5FFC5978400CA257EB9001EEC59/\\$File/Vulvoplasty_Review_Report.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/E393B5FFC5978400CA257EB9001EEC59/$File/Vulvoplasty_Review_Report.pdf)

²⁹ Shahvisi A, Earp BD. The Law and Ethics of Female Genital Cutting. In: Creighton S, Liao L-M, editors. Female Genital Cosmetic Surgery: Interdisciplinary Analysis & Solution. 2018.

³⁰ Attorney General’s Department. Review of Australia’s Female Genital Mutilation legal framework. 2013.

<http://www.ag.gov.au/Publications/Pages/ReviewofAustraliasFemaleGenitalMutilationlegalframework-FinalReportPublicationandforms.aspx>

- “independent, effective **human rights-based oversight mechanism(s)** to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations”⁵

6 Re: Carla

Few cases relating to intersex children are considered by the Family Court. Cases have typically involved sterilisation (irrespective of fertility). *Re: Carla (Medical procedure)* [2016] FamCA 7 was initiated by parents of a child pseudonymously named Carla and adjudicated in Queensland. An anonymous Queensland state government department participated.³

Carla was “born in 2010, is now five years of age and is about to start school”, and “was born with a sexual development disorder” (at [1]), 17-beta hydroxysteroid dehydrogenase 3 deficiency, with XY chromosomes, testes, and predominantly female genitalia. Justice Forrest stated that her sterilisation could “be authorised by either of Carla’s parents”. This has taken such cases out of Court jurisdiction.

Justice Forrest argued that gonadectomy (sterilisation) was justifiable due to a potential “intermediate” cancer risk, with clinical consensus of “risk of germ cell malignancy at ...an intermediate level” (at [19]); it was “virtually impossible to regularly monitor them for the presence of tumours” (at [20]). There is no evidence for this. The cited clinical statement advises that clinicians should “monitor” gonads in children with this intersex trait.³¹ A 2010 clinical review reduced estimates of risk.³² A German multidisciplinary team has advised that monitoring is effective even for “high risk” groups.³³ According to clinical literature, retention and monitoring of gonads should have been uncontentious.

Gender stereotyping substantively comprises the rationale for sterilisation, citing parental reporting and clinical affidavits:

- a. Her parents were able to describe a clear, consistent development of a female gender identity;*
- b. Her parents supplied photos and other evidence that demonstrated that Carla identifies as a female;*
- c. She spoke in an age appropriate manner, and described a range of interests/toys and colours, all of which were stereotypically female, for example, having pink curtains, a Barbie bedspread and campervan, necklaces, lip gloss and ‘fairy stations’;*
- d. She happily wore a floral skirt and shirt with glittery sandals and Minnie Mouse underwear and had her long blond hair tied in braids; and*

³¹ Hughes IA, Houk C, Ahmed SF, Lee PA, LWPES/ESPE Consensus Group. Consensus statement on management of intersex disorders. *Archives of Disease in Childhood*. 2006;91:554–63.

³² Pleskacova J, Hersmus R, Oosterhuis JW, Setyawati BA, Faradz SM, Cools M, et al. Tumor Risk in Disorders of Sex Development. *Sexual Development*. 2010;4(4–5):259–69.

³³ Amnesty International. *First, Do No Harm*. 2017.

e. Her parents told Dr S that Carla never tries to stand while urinating, never wants to be called by or referred to in the male pronoun, prefers female toys, clothes and activities over male toys, clothes and activities, all of which are typically seen in natal boys and natal girls who identify as boys. (at [15])

We note that Australian clinical literature, published in 2009, states:

As is well known, spontaneous change of gender identity from female to male occurs after the onset of puberty in 46,XY children with ... 17 β -hydroxysteroid dehydrogenase deficiency.³⁴

Nevertheless, Justice Forrest suggested that sterilisation should deliberately proceed prior to the child's ability to consent, stating it would be:

less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure (at [30])

Despite justifications for early sterilisation, no such claim was made about trauma arising from a further possible surgery:

Carla may also require other surgery in the future to enable her vaginal cavity to have adequate capacity for sexual intercourse. (at [18])

Carla's medical history was also put before the Family Court:

Surgery already performed on Carla has enhanced the appearance of her female genitalia. (at [2])

In 2014, Carla underwent ... a 'clitoral' recession and labioplasty to feminise Carla's external appearance (at [16])

These interventions, disclosed incidentally to a case brought to sterilise the child, are "vulvoplasties" and so identify cultural norms driving interventions for "congenital malformations". Evidencing State complacency and complicity, a 2012 Queensland government department stated:

Previously it was an accepted practice to assign the external genitalia of a child during their childhood, often through surgical intervention, to determine the sex of the child early in their life. Research and investigation now advises against any irreversible or long-term procedures being performed on intersex children, unless a condition poses a serious risk to their health.³⁵

³⁴ Hewitt JK, Warne GL. Management of disorders of sex development. *Pediatric Health*. 2009;3(1):51–65.

³⁵ Department of Communities. 'Engaging Queenslanders: A Guide to Working with Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Communities'. 2012.