

June 2018

Shadow Report submission to the Committee on the Elimination of Discrimination against Women, on the situation of intersex people in Australia

1 Submitting organisation

This Shadow Report has been written and submitted by **Intersex Human Rights Australia** (IHRA), a national organisation run by and for people born with intersex variations. Formerly known as Organisation Intersex International (OII) Australia, IHRA is a not-for-profit company, with Public Benevolent Institution (charitable) status. We promote the human rights, including the bodily autonomy, of intersex people in Australia, and we provide information and education services.

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2 Summary

The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) seeks to eliminate discrimination against women, including in matters relating to marriage, to health and well-being, and to equality before the courts; the Convention also calls for the elimination of prejudices and customary practices based on gender stereotypes.¹ The joint CEDAW and Committee on the Rights of the Child General Comment 31 on harmful practices calls for the elimination of harmful practices.²

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

² Committee on the Elimination of Discrimination against Women, Committee on the Rights of the Child. Joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child on harmful practices. 2014 Nov. Report No.: CEDAW/C/GC/31-CRC/C/GC/18.

A pattern of human rights abuses on infants, children and adolescents born with intersex traits (variations of sex characteristics) occurs in Australia, without any form of effective, independent scrutiny or oversight, often based on gender stereotypes, and lacking a scientific basis. Evidence of abuses includes the Family Court of Australia case of *Re: Carla (Medical procedure)* which facilitated the unnecessary sterilisation of a 5-year old child, and incidental disclosure in that child's medical history of a medically unnecessary clitorectomy and labioplasty. This was described by the judge, in 2016, in the following ways:

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])

We are not aware of any other country where a member of the judiciary has similarly described a labioplasty and clitorectomy as appearance "enhancing" and without adverse comment. These interventions are abhorrent and indicate a serious gap in legislation preventing female genital mutilation.

The child in this case was described as having a "sexual development disorder", more usually described in clinical settings as a "disorder of sex development". The framing of intersex variations using such terms is itself a disturbing justification of cosmetic (appearance "enhancing") rationales for medical interventions.

In many cases, harmful practices and other human rights abuses occur despite rhetoric by Australian governments that denies or asserts changes to clinical practices, and that asserts the recognition and valuing of intersex people.⁴

In 2013, a Senate Community Affairs References Committee inquiry into the involuntary or coerced sterilisation of people with disabilities, and of intersex people made a series of recommendations for change to clinical practice.⁵ Four years on, the Australian government has rejected the recommendations of that inquiry and both federal and State governments have failed to act. Further, recent Family Court cases show that the judicial system is unable to perform the independent role sought by the Senate inquiry,⁶ and the weight of international evidence calls for stronger, more substantive action. A 2017 Australian-Aotearoa/New Zealand community consensus statement has adopted a set of demands, the Darlington Statement, in response to these deleterious situations.⁷

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

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 <https://twitter.com/deanpwda/status/869848554617151488>

⁶ <https://twitter.com/deanpwda/status/869850421497655296>

⁷ Androgen Insensitivity Support Syndrome Support Group Australia, Intersex Trust Aotearoa New Zealand, Organisation Intersex International Australia, Black E, Bond K, Briffa T, et al. Darlington Statement. 2017. Available from: <https://oii.org.au/darlington-statement/>

We urge the Committee on the Elimination of Discrimination against Women to make strong recommendations in line with recommendations by other UN Treaty Bodies, and in line with recommendations by the Committee to Germany,⁸ to assist in breaking a continuing pattern of deferral and delay without action.

3 Recommendations

In March 2017, more than twenty current and future leaders of the intersex human rights movement in Australia and New Zealand gathered in Darlington, Sydney, and agreed on a common platform. We respectfully request that the Committee acknowledges that platform, the Darlington Statement,⁷ prior concluding observations by the Committee and by other UN Treaty Bodies, and 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.⁹ In particular, to ensure the right of children born with variations of sex characteristics not undergo irreversible cosmetic interventions to “fix” sex characteristics, or otherwise assign sex, “enhance”, or reinforce a sex assignment, when sex characteristics do not fit medical norms for females or males.
2. Implement legislation to prohibit unnecessary surgical or other medical treatment on intersex children (i.e. forced and coercive interventions) until they reach an age at which they can provide their free, prior and informed consent.¹⁰ For example, by criminalising deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent of the recipient.
3. Ensure the mandatory availability of independent, community-run counselling services for all intersex children and their parents.
4. An arbitrary and unclear legal distinction between “therapeutic” and “non-therapeutic” medical interventions ensures that decision-making rationales to manage physical health issues are intertwined with non-therapeutic and cosmetic rationales. The government should ensure that medical interventions necessary for physical health are carefully distinguished from interventions designed to “normalise” bodies of children born with non-normative sex characteristics.
5. Provide redress and access to justice to people who have undergone unwanted sterilisations and other medical interventions to “normalise” sex characteristics.¹¹

⁸ Committee on the Elimination of All Forms of Discrimination against Women, Concluding Observations on Germany, CEDAW/C/CHE/CO/7-8, 2017, para 24(6).

⁹ This wording was adopted by the Committee on the Rights of the Child in Concluding Observations on New Zealand (CRC/C/NZL/CO/5), 2016, para 25; Concluding Observations on South Africa, (CRC/C/ZAF/CO/2), 2016, paras. 39 to 40.

¹⁰ This wording was adopted by the Committee on the Elimination of All Forms of Discrimination against Women in Concluding Observations on Germany, (CEDAW/C/CHE/CO/7-8), 2017, para 24(d).

¹¹ Similar recommendations have been made by the Committee on the Elimination of All Forms of Discrimination against Women in Concluding Observations on Germany, (CEDAW/C/CHE/CO/7-8), 2017, para 24(6).

6. Commit to ensuring the development, with meaningful community participation, of appropriate, transparent, human rights-based standards of care for the treatment of persons born with sex characteristics that do not fit norms for female or male bodies.¹²
7. Ensure that all medical interventions where rationales or justifications are contested are subjected to independent, human rights-based scrutiny, bringing together human rights experts, clinicians and intersex-led community organisations. Ensure that pros and cons for and against necessary medical treatment will be properly ventilated and considered, including the lifetime health, legal, ethical, sexual and human rights implications.
8. Ensure that medical and psychological professionals, and parents, are educated on bodily and sexual diversity and on human rights norms, and on the consequences of unnecessary interventions for children born with non-normative sex characteristics.¹³
9. 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.

¹² Similar relevant recommendations have been made by the Committee on the Rights of the Child in Concluding Observations on New Zealand (CRC/C/NZL/CO/5), 2016, para 25; and the Committee on the Elimination of All Forms of Discrimination against Women in Concluding Observations on France, (CEDAW/C/FRA/CO/7-8), 2016, para 19(f).

¹³ Similar relevant recommendations have been made by the Committee against Torture in Concluding Observations on Germany, (CAT/C/DEU/CO/5), 2011; and the Committee on the Rights of the Child in Concluding Observations on Ireland, (CRC/C/IRL/CO/3-4), 2016, para 40.

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5 Who are intersex people?

IHRA refers to intersex people in this document in line with a definition given in 2016 by the UN Office of the High Commissioner for Human Rights, African Commission on Human and Peoples' Rights, Council of Europe Commissioner for Human Rights, Inter-American Commission on Human Rights and other human rights experts:

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.¹⁴

We use this term to include all people born with bodies that do not fit medical or social norms for male or female bodies. In doing so, we acknowledge the diversity of intersex people in terms of our identities, legal sexes assigned at birth, our genders, gender identities, and the words we use to describe our bodies.

Many forms of intersex exist; it is an umbrella term, rather than a single category. At least 30 or 40 different variations are known to science;¹⁵ most are genetically determined. Since 2006, clinicians frequently use a stigmatising label, “Disorders of Sex Development” or “DSD”, to refer to intersex variations.

Intersex variations can include differences in the number of sex chromosomes, different tissue responses to sex hormones, or a different hormone balance. Examples of intersex variations include androgen insensitivity syndrome (AIS), congenital adrenal hyperplasia (CAH), and sex chromosome differences such as 47,XXY (often diagnosed as Klinefelter syndrome) and 45,XO (often diagnosed as Turner syndrome). Many persons do not have clear genetic diagnoses.¹⁵ Some common intersex variations are diagnosed prenatally,¹⁶ while others may be diagnosed in infancy, early childhood, at puberty or later in life.

¹⁴ Office of the High Commissioner for Human Rights, African Commission on Human and Peoples' Rights, Council of Europe, Office of the Commissioner for Human Rights, Inter-American Commission on Human Rights, Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, et al. Intersex Awareness Day – Wednesday 26 October. End violence and harmful medical practices on intersex children and adults, UN and regional experts urge [Internet]. Office of the High Commissioner for Human Rights; 2016 [cited 2016 Oct 24]. Available from:

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

¹⁵ Hiort O. I-03 DSDnet: Formation of an open world-wide network on DSD at clinician conference, “4th I-DSD Symposium”; 2013: “DSD comprise a heterogeneous group of differences of sex development with at least 40 different entities of which most are genetically determined. An exact diagnosis is lacking in 10 to 80% of the cases”, [cited 1 Jul 2013]. Available from

http://www.gla.ac.uk/media/media_279274_en.pdf

¹⁶ Davis G. The Social Costs of Preempting Intersex Traits. The American Journal of Bioethics. 2013;13(10):51–3.

6 Human rights and intersex people

6.1 The human rights context

The 1948 Universal Declaration of Human Rights states that all “human beings are born free and equal in dignity and rights” (article 1), “without distinction of any kind” (article 2).¹⁷ In September 2015, the UN High Commissioner for Human Rights commented:

Those foundational, bedrock principles of universality and equality mean that all of us, without exception, and regardless of our sex characteristics, are equally entitled to the protections of international human rights law.¹⁸

Several UN Treaty Bodies have already commented on harmful practices on intersex infants, children, adolescents and adults. For example, in 2015 the Committee on the Rights of People with Disabilities (“CRPD”) asked Germany to implement 2011 recommendations on the rights of intersex people made by the Committee Against Torture (“CAT”),¹⁹ including proper informed consent, investigation and redress, and provider training.²⁰ We note that action remains awaited in Germany, and the Committee on the Elimination of All Forms of Discrimination against Women made similar recommendations in 2017.²¹

In 2013, the then Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, condemned “irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed [on intersex children] 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.”²² The Committee on the Rights of the Child (“CRC”) has described such interventions in similar terms,²³ including in relation to practices by our neighbour, New Zealand.²⁴

The joint CEDAW/CRC General Comment on harmful practices recognises, in paragraphs 6 and 7:

the gender dimension of violence and indicate that sex- and gender-based attitudes and stereotypes, power imbalances, inequalities and discrimination

¹⁷ United Nations, Office of the High Commissioner for Human Rights. Universal Declaration of Human Rights [Internet]. [cited 2015 Nov 26]. Available from:

http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf

¹⁸ United Nations High Commissioner for Human Rights. Opening remarks by Zeid Ra’ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert meeting on ending human rights violations against intersex persons [Internet]. 2015 [cited 2015 Sep 16]. Available from:

<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431&LangID=E>

¹⁹ CAT/C/DEU/CO/5, 12 December 2011

²⁰ CRPD/C/DEU/CO/1, 17 April 2015

²¹ CEDAW/C/DEU/CO/7-8, 3 March 2017

²² A.HRC.22.53. 2013, 1 February 2013

²³ For example, in CRC/C/GBR/CO/5, 3 June 2016

²⁴ CRC/C/NZL/CO/5, 7 October 2016

perpetuate the widespread existence of practices that often involve violence or coercion ... justified by invoking sociocultural and religious customs and values, in addition to misconceptions relating to some disadvantaged groups of women and children²

Paragraph 9 notes:

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

Paragraph 42 comments on the perpetuation of “legal provisions that justify, allow or lead to harmful practices” and paragraph 44 addresses a lack of adequate or effective review by the State and judicial bodies:

Prejudices and weak capacity to address the rights of women and children among judges in customary and religious courts or traditional adjudication mechanisms and the belief that matters falling within the purview of such customary systems should not be subjected to any review or scrutiny by the State or other judicial bodies deny or limit the access to justice of victims of harmful practices²

These issues are evident in the treatment of children born with intersex variations, exemplified in recent Family Court of Australia cases, alongside the absence of “rights-based social and cultural norms” to protect the rights of children born with intersex variations.

In late 2017, the UN Human Rights Committee responded to concerns raised about practices in Australia, made in a submission by IHRA endorsed by the AIS Support Group Australia, Disabled People’s Organisations of Australia, National LGBTI Health Alliance, and People with Disability Australia.²⁵ The response cited ICCPR Treaty articles on non-discrimination (articles 3 and 24), protection from torture and experimentation (article 7), the right to liberty and security (article 9), privacy (article 17), and equality before the law (article 26).²⁶ These citations highlight the many ways in which current medical practices in Queensland and elsewhere in Australia violate our human rights:

25. The Committee is concerned that infants and children born with intersex variations are sometimes subject to irreversible and invasive medical interventions for purposes of gender assignment, which are often based on stereotyped gender roles and are performed before they are able to provide fully informed and free consent (arts. 3, 7, 9, 17, 24 and 26).

²⁵ Carpenter M, Organisation Intersex International Australia. Shadow Report submission to the Human Rights Committee on the situation of intersex people in Australia. 2017 Aug [cited 2018 Mar 30]. Report No.: INT/CCPR/CSS/AUS/28771. Available from: <https://ihra.org.au/31568/shadow-report-iccppr-2017/>

²⁶ Human Rights Committee. Concluding observations on the sixth periodic report of Australia. 2017 Dec. Report No.: CCPR/C/AUS/CO/6.

26. The State party should give due consideration to the recommendations made by the Senate Standing Committee on Community Affairs in its 2013 inquiry report on involuntary or coerced sterilisation of intersex people, and move to end irreversible medical treatment, especially surgery, of intersex infants and children, who are not yet able to provide fully informed and free consent, unless such procedures constitute an absolute medical necessity

6.2 Protecting bodily integrity

The *Darlington Statement* is a community consensus statement by Australian and Aotearoa/New Zealand intersex organisations and advocates, signed in March 2017.²⁷ It provides a statement about our heterogeneity, acknowledging:

3. *The diversity of our sex characteristics and bodies, our identities, sexes, genders, and lived experiences. We also acknowledge intersectionalities with other populations, including same-sex attracted people, trans and gender diverse people, people with disabilities, women, men, and Indigenous - Aboriginal and Torres Strait Islander, Tangata Whenua - and racialised, migrant and refugee populations.*
4. *That the word 'intersex', and the intersex human rights movement, belong equally to all people born with variations of sex characteristics, irrespective of our gender identities, genders, legal sex classifications and sexual orientations.*

The *Darlington Statement* identifies our core human rights concerns as including:

5. *Our rights to bodily integrity, physical autonomy and self determination.*

Key relevant concerns identified in the Statement are:

- B. *We observe that, despite the best efforts of intersex human rights defenders, discrimination, stigmatisation and human rights violations, including harmful practices in medical settings, continue to occur in Australia and Aotearoa/New Zealand.*

Relevant consequential demands include:

7. *We call for the immediate 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. We call for freely-given and fully informed consent by individuals, with individuals and families having mandatory independent access to funded counselling and peer support.*

²⁷ Androgen Insensitivity Syndrome Support Group Australia, Intersex Trust Aotearoa New Zealand, Organisation Intersex International Australia, Black E, Bond K, Briffa T, et al. Darlington Statement. Sydney, NSW; 2017 Mar. Available from: <http://darlington.org.au/statement/>

Paragraph 7 seeks to address a question of necessity by focusing on whether or not it is possible to defer a procedure on a child until they are old enough to provide informed consent, supported by access to peers.

17. *We call for the implementation of advisory bodies to develop appropriate **human rights-based, lifetime, intersex standards of care** with full and meaningful participation by intersex community representatives and human rights institutions.*
21. *We call for the provision of alternative, 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. The pros and cons for and against medical treatment must be properly ventilated and considered, including the **lifetime health, legal, ethical, sexual and human rights implications**.*

Standards of care and oversight are required to tackle cases where non-deferrable medical necessity is asserted, and where informed consent to irreversible procedures to modify the sex characteristics of minors is asserted. Standards of care and oversight need to address lifelong health issues, including health issues consequential to early medical interventions. This demand provides for some flexibility in how it might be met, but guardianship tribunals may be appropriate bodies to facilitate such oversight. Standards of care must affirm the human rights of infants, children and adults and provide benchmarks and standards for medical interventions. Current and historical guidelines and principles have been non-binding and have facilitated human rights violations.

19. *We recognise that **intersex people have health and medical needs**, sometimes related to having an intersex variation, and sometimes not. We recognise that for people with an intersex variation, misconceptions and associated stigma can act as barriers to treatment. Current practices are often based on the needs of other populations.*
22. *We call for resourced access to necessary and appropriate health, medical and allied services and treatment, including surgeries and hormone treatment, psychosocial, psychosexual and psychological support, and including reparative treatments. **Standards of care** must support reparative treatments, and must not require conformity with stereotypical and clinical norms for female or male bodies, women and men, nor impose inappropriate psychiatric eligibility assessments.*
23. *Multi-disciplinary teams must operate in line with transparent, **human rights-based standards of care** for the treatment of intersex people and bodies. Multi-disciplinary teams in hospitals must include human rights specialists, child advocates, and independent intersex community representatives.*

The *Darlington Statement* is consistent with a global intersex community statement: the 2013 *Malta Declaration*.²⁸

6.3 The unnecessary medicalisation of intersex bodies

6.3.1 A policy of concealment

Medical practices have historically – and may still currently – be grounded in a model of concealment. In 1998, Cheryl Chase discussed what Kipnis and Diamond consider an ‘epistemological black hole’ that Chase notes ‘precludes follow-up of intersex surgeries’:

*the purpose of surgery is to hide intersexuality, therefore intersexuals must be lied to about their histories and surgeries, and thus follow-up cannot be done because the patients would learn the truth.*²⁹

In 2018, the New Zealand Office of the Privacy Commissioner stated:

*The recommended medical approach in the latter half of the twentieth century was to treat patients with ‘normalisation’ procedures, including surgery, and to raise the individual according to their normalised sex, often without providing full information to the patient as they grew up. Over the past 15-20 years, leading health professionals internationally have advocated for talking with children and young people in age- appropriate ways about their diagnosis and any treatment they might have had. The extent to which this more open practice has been taken up in New Zealand seems to be variable, so some people will have grown up knowing about their diagnosis and treatment, while others will not.*³⁰

Australia and New Zealand share medical and clinical associations, and the same variability exists in current practices in Australia. Additionally, individuals who exited the paediatric hospital system at age 18 during the existence of current or historic policies of concealment may remain unaware of the nature of medical interventions that they have experienced.

6.3.2 Partial information disclosure

Parents may be told skewed and partial information about their child in ways that have a direct impact on the medical interventions experienced by their child. Streuli and others, for example, have identified how:

²⁸ Third international intersex forum. Malta Declaration: Public statement by the third international intersex forum [Internet]. Floriana, Malta; 2013 Dec [cited 2018 Mar 30]. Available from:

<https://ihra.org.au/24241/public-statement-by-the-third-international-intersex-forum/>

²⁹ Chase C. Surgical Progress Is Not the Answer to Intersexuality. *Journal of Clinical Ethics*. 1998;9(4):385–92.

³⁰ Blackwood V, Office of the Privacy Commissioner. Handling health information of intersex individuals [Internet]. Office of the Privacy Commissioner. 2018 [cited 2018 Mar 7]. Available from: <https://www.privacy.org.nz/blog/handling-health-information-of-intersex-individuals/>

Parental decisions concerning early sex assignment surgery for DSD children depend on the health professional counseling received, to a degree of which neither parents nor professionals appear fully aware.³¹

Furthermore, silence and secrecy mean that there is no longitudinal research underpinning irreversible clinical practices, their necessity, indications, timing or even evaluation.

Current protocols, set out in a 2006 Chicago ‘Consensus statement on management of intersex disorders’ suggested that: ‘Appearance-altering surgery is not urgent’ yet, at the same time, it states explicit rationales for ‘early reconstruction’ including ‘minimizing family concern and distress’ and ‘mitigating the risks of stigmatization and gender-identity confusion’.³²

Clinicians and parents may make decisions based upon delivery room distress,³³ and social and cultural bias. Julie Greenberg states that:

safeguards are needed because parents may be making decisions at a time when they are suffering distress about giving birth to and raising an “abnormal” child. Under these circumstances, it is difficult for parents to objectively determine the treatment that would be in their child’s long term best interests, especially because the issue may affect sexuality when the child becomes an adult.³⁴

In a clinical study of parents of intersex children, Dayner, Lee and Houk surveyed the perspectives of 21 parents of 17 children with XX sex chromosomes and congenital adrenal hyperplasia, finding that 100% of parents agreed surgery was ‘done for more “natural looking” genitalia’, and 95% ‘would consent to surgery if adult sexual sensation reduced’.³⁵ However, Liao et al report that ‘parental regret can be high’,³⁶ and parents ‘may not realise that they are de facto opting for experimental surgery on their children’,³⁶ with no credible

³¹ Streuli JC, Vayena E, Cavicchia-Balmer Y, Huber J. Shaping Parents: Impact of Contrasting Professional Counseling on Parents’ Decision Making for Children with Disorders of Sex Development: Parent Decision in Disorders of Sex Development. *The Journal of Sexual Medicine*. 2013 Aug;10(8):1953–60.

³² Houk CP, Hughes IA, Ahmed SF, Lee PA, Writing Committee for the International Intersex Consensus Conference Participants. Summary of Consensus Statement on Intersex Disorders and Their Management. *PEDIATRICS*. 2006;118(2):753–7.

³³ Department of Health and Human Services. Ambiguous genitalia in neonates [Internet]. 2015 [cited 2017 Apr 2]. Available from: <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/congenital-abnormalities/ambiguous-genitalia>

³⁴ Greenberg JA. *Intersexuality and the Law: Why Sex Matters*. New York: New York University Press; 2012.

³⁵ Dayner JE, Lee PA, Houk CP. Medical Treatment of Intersex: Parental Perspectives. *Journal of Urology*. 2004;172(4):1762–5.

³⁶ Liao L-M, Wood D, Creighton SM. Parental choice on normalising cosmetic genital surgery. *BMJ*. 2015;351:h5124.

non-surgical treatment pathways. In 2016, a co-author of that editorial stated in a clinical conference abstract:

Many multidisciplinary teams are led by surgeons committed to genital surgery. In addition complex invasive surgery may be reimbursed at high tariffs for health care providers. Psychological support – although less costly – is often patchy or unavailable...

Credible non-surgical pathways with ongoing psychological support for the family currently do not exist.³⁷

We note from clinical literature published in 2016 that there remains no clinical consensus regarding indications, timing, procedure or evaluation of surgical interventions to ‘normalise’ intersex bodies. A ‘Global Disorders of Sex Development Update since 2006’ states regarding genital surgeries:

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 ... Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. 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.³⁸

In 2017, the Committee on Bioethics of the Council of Europe commissioned a report examining the rights of children in biomedicine. The report authors made extensive comments and citations, including citing clinical literature showing that:

(1) “quality of life” studies on patients into adulthood are lacking and are “poorly researched”, (2) the overall impact on the sexual function on children surgically altered is “impaired” and (3) the claim that gender development requires surgery is a “belief” unsubstantiated by data...

On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion³⁹

³⁷ Creighton S. Surgical Management of DSD: New Insights. 2016 Aug 19 [cited 2016 Aug 31]; Available from: <http://abstracts.eurospe.org/hrp/0086/hrp0086con1.2.htm>

³⁸ Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, Baratz A, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. Hormone Research in Paediatrics. 2016;85(3):158–180.

³⁹ Zillén K, Garland J, Slokenberga S, Committee on Bioethics of the Council of Europe. The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties. 2017.

The report of the Committee on Bioethics found that:

- *surgery ... in infancy [is done] on the assumption that parental rearing could steer gender development.*
- *all evidence-based reviews concur that gender identity and sexual orientation of children with differences in sex development cannot be predicted with accuracy*
- *the medical literature has not addressed the implications of whether clinicians and parents have a right to assign these identities surgically and irreversibly on children³⁹*

It stated 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 appearance³⁹

Surgeries do not create 'normal' bodies: early surgeries create bodies that need further surgeries due to physical development during adolescence; sterilisations create bodies that have a lifelong need for hormone treatment; scarring creates visible difference; and all surgeries affect physical sensitivity.⁴⁰

However, parents and individuals subjected to medical intervention may be unaware that early interventions lack firm evidence and lack clinical consensus. Parents and caregivers may also have no idea that early medical interventions may trigger a lifetime of medical interventions and surgeries.

7 The Australian policy context

7.1 Intertwined therapeutic and non-therapeutic rationales

In 2013, a new attribute of 'intersex status' based upon physical features was added to federal anti-discrimination law,⁴¹ and an inquiry into the involuntary or coerced sterilisation of people with disabilities, and of intersex people, was held by the Senate of Australia. The Senate inquiry process documented current medical practices and rationales,⁴² understood to be reflected in a public submission to the Senate inquiry by the Australasian Paediatric

⁴⁰ See note 29 and: Australian Senate Community Affairs References Committee. Hearing: Involuntary or coerced sterilisation of people with disabilities in Australia. Thursday 28 March 2013, Hansard [Internet]. Canberra; Mar 28, 2013. Available from: <http://www.aph.gov.au/hansard>

⁴¹ ComLaw. Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013 [Internet]. Available from: <http://www.comlaw.gov.au/Details/C2013A00098/>

⁴² Australian Senate, Community Affairs References Committee. Involuntary or coerced sterilisation of intersex people in Australia [Internet]. Canberra: Community Affairs References Committee; 2013 [cited 26 Oct 2013]. Available from:

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

Endocrine Group (APEG). That submission suggested that 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.⁴³

Management of high cancer risks and urinary issues should not be controversial. However, documentation suggests that such issues are intertwined with non-therapeutic rationales for treatment.

A legal distinction between therapeutic and non-therapeutic treatment became part of Australian common law as a result of a 1992 judgment known as ‘Marion’s Case’. The ruling asserted a ‘necessary’ distinction between therapeutic and non-therapeutic treatment, despite lack of clarity about how the distinction is made. Therapeutic treatment, including incidental sterilisation, may broadly be considered to involve treatment of a malfunction or disease; this can be authorised by guardians as necessary, without court approval.⁴⁴

However, a submission to the 2013 Senate inquiry by Cools and others shows how distinctions between therapeutic and non-therapeutic are arbitrary and can be intertwined, having lost any relationship to medical necessity for reasons of physical health. Specifically, a quotation from that private submission quoted in the Senate committee report shows how decision-making on sterilisation incorporates factors unrelated to physical health risks, and how this is assessed prior to a child’s ability to freely express an identity:

In any individual with a DSD condition, the decision to perform gonadectomy is reached by weighing benefits and risks of various issues, such as risk for [germ cell tumour], sex of rearing, estimated capacity of the gonad to produce hormones in accordance with or opposite to sex of rearing and/or (developing) gender identity, likelihood of gender dysphoria later in life, etc.⁴⁵

⁴³ Australasian Paediatric Endocrine Group, Hewitt J, Warne G, Hofman P, Cotterill A. 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 [Internet]. Jun 2013 [cited 28 Jun 2013]. Available from: <http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>

⁴⁴ Department of Health & Community Services v JWB & SMB (‘Marion’s Case’) [1992] 175 CLR 218 at [48].

⁴⁵ Cools M, Dessens A, Drop S, Hewitt J, and Warne G. Answers to questions on notice (received 27 Sep 2013). In Australian Senate, Community Affairs References Committee. Involuntary or coerced sterilisation of intersex people in Australia [Internet]. Canberra; 2013 [cited 26 Oct 2013]. Available from:

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

In relation to cancer risks, actual risk levels are poorly understood in many cases; to a significant extent, this is due to the high prevalence of gonadectomies (sterilisations) in affected populations and a resulting inability, in high income countries, to establish control groups monitoring risk levels in intact individuals. A German multidisciplinary team advised Amnesty International this year that, in any case, ‘cancer risk even for the high risk groups is not so high. We can monitor with ultrasound and for tumour markers’.⁴⁶

The Senate Committee was ‘disturbed’ by the encapsulation of different rationales evidenced in clinical literature and submissions:

*This kind of encapsulation of factors ... might happen because of the distinction made by Australian courts between 'therapeutic' and 'non-therapeutic' medical intervention. Treating cancer may be regarded as unambiguously therapeutic treatment, while normalising surgery may not. Thus basing a decision on cancer risk might avoid the need for court oversight in a way that a decision based on other factors might not. The committee is disturbed by the possible implications of this.*⁴²

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.*⁴³

We regard these as cultural, not functional, requirements for cosmetic interventions; and the stated psychosocial rationales lack evidence of necessity. Subsequent to such interventions APEG notes:

*particular concern regarding sexual function and sensation*⁴³

This issue has been raised in Australia over two decades, yet such interventions continue. For example, in 2004 Tony Briffa (a co-executive director of IHRA) wrote in a letter published in *Nature*:

*the lasting effects of reducing potential for full enjoyment of sexual experiences are often ignored — along with a person’s right to make informed decisions.*⁴⁷

No long-term follow-up takes place in Australia,⁴³ and handover from paediatric to adult services results in poor access to healthcare by adults, and a lack of clinical data on adult

⁴⁶ Amnesty International. First, Do No Harm. London: Amnesty International; 2017 May. Report No.: EUR 01/6086/2017.

⁴⁷ Briffa T. Intersex surgery disregards children’s human rights. *Nature*. 2004 Apr 15;428:695.

outcomes. Paediatric services are anyway poorly placed to determine long term outcomes, as they focus on only one single stage in the human lifecycle. Indeed, internationally, Creighton and others state that:

a schism has developed between clinicians working in paediatric and in adolescent/adult services. This has led to the defence of standard surgical practices by some paediatric clinicians against increasing interrogation of the practice by clinicians looking after adolescent and adult patients.⁴⁸

In contrast, intersex peer support and advocacy organisations are fully cognisant of our health and human rights issues across the full human lifecycle.

In its 2013 report responding to submissions on involuntary or coerced sterilisation, 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.⁴²

The core issue here is that medical professionals are defining interventions, including so-called 'normalising' interventions conducted for social and cultural reasons, as therapeutic. However, these rationales and procedures are contested, and they lack both clinical consensus and evidence.

7.2 Non-implementation of Senate report

The cross-party Senate report on involuntary or coerced sterilisation of intersex people called (on page 74) for protocols and guidelines consistent with recommendations by Intersex Human Rights Australia (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

⁴⁸ Creighton SM, Michala L, Mushtaq I, Yaron M. Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same? *Psychology and Sexuality*. 2014;5(1):34–43.

be consistent with Organisational Intersex International's recommendations, particularly 4, 5 and 6.⁴²

Those recommendations numbered 4, 5 and 6 are:

- 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. (para 3.114)⁴²*

The Senate also provided guidance on implementing a human rights-affirming framework for such interventions:

3.97 The evidence suggests that a human rights consistent framework ... must necessarily operate from a presumption in favour of maintaining the [child's bodily] status quo for as long as possible except where such a presumption would conflict with the child's best interests. A model that confers rights on third parties, through substitute decision making, before it guarantees the rights of the child, is likely to be a disproportionate limitation of the child's right to autonomy/self-determination.⁴²

In its 2015 response to the cross-party Senate inquiry, the federal government stated that 'the substantive regulation of medical treatment is a matter for state and territory governments'.⁴⁹ The government commended controversial and ineffective 2013 ethical guidelines produced in the State of Victoria that we discuss below.

No Australian government has implemented recommendations from the 2013 Senate committee report and, in May 2017, the report appears to have been finally rejected by the federal government.⁴⁹ No governmental attempts at redress have been made in Australia. The inclusion of 'intersex status' in anti-discrimination law appears not to have impacted upon harmful practices in institutional settings.

7.3 Flawed principles and derivative guidelines

A 2010 clinical ethical framework for the treatment of children with intersex variations was developed by Gillam, Hewitt and Warne at the Royal Children's Hospital, Melbourne, the University of Melbourne, and the Murdoch Children's Research Institute, Melbourne.⁵⁰ That

⁴⁹ Attorney General's Department. Australian Government response to the Senate Community Affairs References Committee reports on involuntary or coerced sterilisation. 2015 May.

⁵⁰ 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.

framework states 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 relationships⁵⁰*

The inclusion of a risk related to impaired marriage prospects is, internationally, highly unusual, but it demonstrates the marked similarity between rationales favouring genital interventions on intersex children and rationales favouring Female Genital Mutilation in countries where that practice remains a norm. Given that marriage in Australia excluded same-sex couples until December 2017, such rationales are also heteronormative, promoting a heterosexual ideal on people born with intersex bodies.

The 2010 paper was criticised by some clinicians at the time, as focused on the continuing justification of surgical interventions, rather than alternative approaches that tackle stigma and shame. The paper was described as:

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

Further:

The authors have opted to ignore the existing DSD ethics literature in an effort to arrive at principles putatively unburdened by previous ethical engagement.⁵¹

The methodology employed to develop the principles was described as reflective equilibrium. In this context, it appears that a small and homogeneous set of stakeholders (the three authors) established a set of principles without reference to external, dissenting or diverse viewpoints, and thus constructed a narrow position that is not defensible. Nevertheless, the authors have suggested that their ethical guidance was rolled out nationally.⁵²

In 2013, a derivative ethical framework on the management of intersex infants, children and adolescents was published by the State of Victoria in 2013, with limited input from community organisations. This derivative ethical framework claims:

⁵¹ 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.

⁵² Gillam LH, Hewitt JK, Warne GL. Ethical Principles: An Essential Part of the Process in Disorders of Sex Development Care. Hormone Research in Paediatrics. 2011;76(5):367–8.

In the past, the birth of an infant born with an intersex condition was viewed as a medical and social ‘emergency’. In some cases parents report not having been given adequate information, time or options to provide informed consent or make informed decisions on behalf of their children.⁵³

However, these issues persist today. In 2015, Victoria’s Department of Health and Human Services published a Neonatal Handbook for clinicians that directly contradicted the Department’s own 2013 ethical framework. It described the birth of an infant with ambiguous genitalia as:

rarely anticipated and can be a source of great distress for parents, delivery room and nursery staff.⁵⁴

*The situation should be treated as a medical emergency ...
Corrective surgery is usually undertaken within the first year of life but timing can be controversial. Very early surgery at under six months of age is less commonly performed than in the past⁵⁴*

This material was removed from the Department’s website in April 2017,⁵⁵ in response to previous public disclosure of such material by IHRA (then OII Australia), including a submission to the Committee Against Torture in June 2016.⁵⁶ There is no evidence that the removal of this material from the Department’s website has had any impact on clinical practices.

The Department currently (as at 1 May 2018) makes the following statements about children born with congenital adrenal hyperplasia:

*Potential for cosmetic surgical correction of **ambiguous genitalia** for virilised [sic] females should be discussed with the endocrinologist. Most surgical*

⁵³ Victoria, Department of Health. Decision-making principles for the care of infants, children and adolescents with intersex conditions [Internet]. 50 Lonsdale Street, Melbourne: Victorian Government; Feb 2013 [cited 27 Feb 2013]. Available from:

<http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions>

⁵⁴ Department of Health and Human Services. Ambiguous genitalia in neonates [Internet]. 2015 [cited 2017 Apr 2]. Available from: <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/congenital-abnormalities/ambiguous-genitalia>

⁵⁵ OII Australia. Gaslighting in Victoria [Internet]. 2017 May 18 [cited 2017 May 18]. Available from <https://oii.org.au/31391/gaslighting-in-victoria/>

⁵⁶ Carpenter M, Organisation Intersex International Australia. Contribution to the List of Issues Prior to Reporting to the Committee against Torture for Australia [Internet]. Sydney; 2016 Jun [cited 2016 Jun 29]. Available from: <https://oii.org.au/30546/loi-cat-review/>

correction is now delayed until 6 months of age or later. Opinion currently varies between centres as to surgical management options.⁵⁷

That is, it is up to multidisciplinary clinical teams to make their own judgements about indications and techniques for surgery. The Department's current (as at 1 May 2018) 'Better Health' page on congenital adrenal hyperplasia states:

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 adolescence, before the menstrual periods begin.⁵⁸

This description matches the description for 'vulvoplasties' in Medicare and AIHW data.

The 2013 Victorian guidelines have demonstrably not been binding on either the State or its hospitals, and have been disregarded in subsequent Departmental policy. Nevertheless, the guidelines were commended in the government's response to the Senate Community Affairs References Committee reports on involuntary or coerced sterilisation (see, for example, page 19).⁴⁹ IHRA does not support the guidelines as they do not provide human rights-based standards of care.

Queensland has also published an endorsement of current practices, including conceptions of 'normality' and 'gender affirmation'; that is, language borrowed from the treatment of trans persons exercising their capacity to affirm their internal identity, but in children who may not be in a position to affirm or contribute to decision-making. The 2016 Queensland Sexual Health Strategy illustrates a deeper problem:

Informed consent from legal guardians is also essential if treatment is to be undertaken on children and young people later in life for normalisation and gender affirmation...

⁵⁷ Department of Health & Human Services. Congenital adrenal hyperplasia (CAH) in neonates [Internet]. [cited 2017 Jun 8]. Available from: <https://www2.health.vic.gov.au:443/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/conditions/congenital-adrenal-hyperplasia>

⁵⁸ Department of Health & Human Services. Congenital adrenal hyperplasia (CAH) [Internet]. 2014 [cited 2016 Jun 8]. Available from: <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/congenital-adrenal-hyperplasia-cah>

Medical treatment is sometimes necessary to help development proceed as normally as possible and for some conditions, surgical treatment may be recommended⁵⁹

However, as the 2013 Senate cross-party 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'.¹²⁶ The Androgen Insensitivity Syndrome Support Group Australia held a similar view of current medical practice...

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 in areas such as the application of the Prader scale, or how medical specialists learn about the diversity of appearance of genitals or how they define 'normal' in their clinical practice.⁴²

In the few cases where it has provided oversight, the Family Court has been unable to respond to such issues.

7.4 Data on human rights violations in medical settings

Little statistical information is available on historic and current medical practices, though we are given to understand from discussions with clinicians that individual multidisciplinary teams know very little about the actual practices of other teams, and a high degree of variability in practices was reported to the Senate in 2013.⁴⁰ Factors driving this variability may include , multidisciplinary team leadership, and clinician specialism, age and gender, personal dispositions and beliefs about concepts of normality, sex and gender.⁶⁰

Limited information becomes periodically available from hospitals in press reports and peer-reviewed journals, indicating that information is stored, albeit carefully curated. For example, 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' each year.⁶¹ Variability between hospitals and their lack of transparency negate broad or unsubstantiated claims of change to clinical practices and surgery numbers.

⁵⁹ Queensland Health. Queensland Sexual Health Strategy [Internet]. 2016 Dec [cited 2017 Jul 4]. Report No.: QH845 11/16. Available from: <https://www.health.qld.gov.au/public-health/topics/sexual-health/strategy>

⁶⁰ See, for example, note 37 and Reitsma W, Mourits MJE, Koning M, Pascal A, van der Lei B. No (Wo)Man Is an Island-The Influence of Physicians' Personal Predisposition to Labia Minora Appearance on Their Clinical Decision Making: A Cross-Sectional Survey: Labia Minora Reductions: Physicians' View. The Journal of Sexual Medicine. 2011 Aug;8(8):2377–85.

⁶¹ Bock A. It takes more than two. The Age. 2013 Jun 20; Available from: <http://www.theage.com.au/national/it-takes-more-than-two-20130619-2oj8v.html>

Some national data on surgical procedures by the Australian Institute of Health and Welfare is currently available for some periods.⁶² The data available for the year 2013-2014 showed a national total of 6 ‘procedures for anomalies of genitalia’ in female-assigned age groups 0-19 years.⁶³ However, this is contradicted (and exceeded) in a contemporaneous disclosure by a single hospital to the media (the Royal Children’s Hospital Melbourne, as mentioned above) suggesting that data are displaced to other, potentially less contentious, procedure codes. In a submission to a national inquiry, Morgan Carpenter reported:

2014 Department of Health Medicare Benefits Schedule Review on “vulvoplasties”⁶⁴ identifies 371 Medicare-funded vulvoplasties for “congenital malformations” during the period 2007/8 to 2011/2; an average of 74.2 per year.⁶⁵ Medicare procedures data published by the Australian Institute of Health and Welfare (AIHW) show an average of 71.5 vulvoplasties per year in children aged under 15 between 2002/3 and 2014/5, with a range from 57 to 95 procedures per year.⁶⁶ These data are not associated with diagnostic data or claimed rationales for interventions.

The same AIHW data also show that the numbers of vulvoplasties in the 0-19 year age groups have increased significantly from 101 in 2002/3 to 258 in 2015/5.

The number of masculinising surgeries shows no particular trend over the period from 2002/3 to 2014/5. Of particular note, the Institute reports 200 repeat surgeries on persons aged under 20 for ‘repair of postoperative urethral fistula’ in 2013/4, including 125 such repeat procedures in children aged 1 to 4 years. To be clear, these are follow-up surgeries for iatrogenic conditions, caused by prior medical intervention.

⁶² This information is extracted from: Carpenter M. The ‘normalisation’ of intersex bodies and ‘othering’ of intersex identities, the experience in Australia. In: Scherpe J, Dutta A, Helms T, editors. The Legal Status of Intersex Persons. 1st ed. Cambridge, England: Intersentia; 2018 (forthcoming).

⁶³ Australian Institute of Health and Welfare. Procedures data cubes [Internet]. 2017 [cited 2017 Feb 27]. Available from <http://www.aihw.gov.au/hospitals-data/procedures-data-cubes/>

⁶⁴ Defined in the Review as ‘any surgery performed on the outside female genital structures’ thereby including labioplasties and clitorectomies

⁶⁵ Department of Health. MBS Reviews Vulvoplasty Report [Internet]. Department of Health; 2014 Apr [cited 2017 Sep 30]. Available from:

[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)

⁶⁶ Australian Institute of Health and Welfare. Procedures data cubes. 2002-2017 [Internet]. 2017 [cited 2017 Sep 30]. Available from: <http://www.aihw.gov.au/hospitals-data/procedures-data-cubes/>

Research to be published ... shows that there is no evidence of any reduction in the number of surgeries relevant to children born with intersex variations over the period 2002/3 to 2014/5.⁶⁷

7.5 Female genital mutilation

Female Genital Mutilation refers to all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for ‘non-medical reasons’.⁶⁸ International health and human rights institutions state that the practice continues in many parts of the world, due to gender inequality, traditional and normative gender roles, including perceptions that the ritual facilitates women’s fuller participation in society, and that the procedure prepares women for adulthood.⁶⁸

UN institutions recognise that, in some cases, parents may be motivated to consent to female genital motivation because they see other parents doing so, while women subjected to the procedure may also exert pressures that promote conformity and ostracize others.⁶⁹ Personal consent is not recognised as a justification for FGM. The World Health Organization and other bodies recognize that medicalization, including as a form of harm reduction, does not justify FGM.⁶⁸

Despite this prohibition of FGM, labioplasties and other vulvoplasties, including for aesthetic purposes, are permitted.⁷⁰ The Department of Health has investigated a ‘marked increase’ of 105% in numbers of Medicare-funded vulvoplasties and labioplasties in adolescents and adults between 2003/4 and 2012/13.⁶⁵

Aesthetic rationales for surgery appear in promotional literature on labioplasties produced by Australian plastic surgeons. It is not clear on what basis such practices can be supported when conducted for cosmetic or aesthetic reasons, other than by the informed consent of the recipient.

⁶⁷ Carpenter M. The ‘normalisation’ of intersex bodies and ‘othering’ of intersex identities, the experience in Australia. In: Scherpe J, Dutta A, Helms T, editors. *The Legal Status of Intersex Persons*. 1st ed. Cambridge, England: Intersentia; 2018 (forthcoming).

⁶⁸ World Health Organization, Office of the High Commissioner for Human Rights, UNAIDS, UNDP, UNECA, UNESCO, et al. *Eliminating female genital mutilation: an interagency statement*. Geneva: World Health Organization; 2008.

⁶⁹ Committee on the Elimination of Discrimination against Women, General Comment 31, and Committee on the Rights of the Child, General Comment 18 (CEDAW/C/GC/31-CRC/C/GC/18), 2014, para 57

⁷⁰ Kennedy A. Mutilation and Beautification. *Australian Feminist Studies*. 2009 Jun 1;24(60):211–31. Spriggs M. Parent-led request for female genital cosmetic surgery in an adolescent. In: McDougall R, Delany C, Gillam L, editors. *When Doctors and Parents Disagree: Ethics, Paediatrics and the Zone of Parental Discretion*. Annandale, NSW: Federation Press; 2016. p. 227–43.

Spriggs M, Gillam L. Body Dysmorphic Disorder: Contraindication or Ethical Justification for Female Genital Cosmetic Surgery in Adolescents: Body Dysmorphic Disorder. *Bioethics*. 2016;30(9):706–13. 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*. Cambridge, England: Cambridge University Press; 2018.

Exemptions in the Model Criminal Code do not apply to cosmetic interventions. However, exemptions in Australian Jurisdictions dealing with female genital mutilation reflects profound confusion about intersex, as they appear to describe intersex infants as ‘neither female or male’, regardless of their actual sex assignment, until they receive surgical reinforcement of those sex assignments. The Model Code permits genital surgeries on intersex people as ‘sexual reassignment procedures’ that ‘give a female, or a person whose sex is ambivalent,[sic] the genital appearance of a particular sex’.⁷¹ This policy framework does not discuss issues of necessity or evidence in support of medical interventions, perhaps assuming that medical interventions will be supported by both. However, neither are the case for infants and children with intersex variations. Actual rationales, including parental distress and cosmetic issues (such as appearance enhancement, marriageability) mirror the rationales evident for FGM in societies where FGM is the norm.

8 Family Court cases on the treatment of intersex children

Few cases on the treatment of intersex children are put to the Family Court for consideration. Such cases have typically involved sterilisation (irrespective of fertility) or been incidental to treatment for gender dysphoria in an intersex child. In each situation, the individuals consequently require a lifetime of hormone replacement. It is notable that relevant Family Court cases rarely employ the term intersex, nor the current clinical term ‘disorders of sex development’; they most frequently refer to a specific intersex variation using a diagnostic term.

A subset of recent and recently cited cases is discussed in this section. They include cases before the federal Family Court in both 2016 and 2017 that demonstrate what Melinda Jones describes as ‘the culpability of health systems and the medical profession’ and a ‘failure of the state to protect the rights’ of children with intersex variations.⁷² A third 1993 case cited by the then Chief Justice of the Family Court in her submission to the 2013 Senate inquiry is also discussed.⁷³ The cases give rise to serious concerns about equality before the courts and tribunals, including access to justice, undue restrictions on legal capacity, and legal and governmental complicity in harmful, current clinical practices.

Last year, the government announced a review of the family law system. In recent weeks, and pre-empting the conclusions of that review, the government has published an intention

⁷¹ Attorney General’s Department. Review of Australia’s Female Genital Mutilation legal framework - Final Report [Internet]. 2013 May [cited 2013 May 25]. Available from:

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

⁷² Jones M. Children’s Health Rights and Gender Issues. In: Children’s Rights in Health Care. Leiden: Brill; (forthcoming).

⁷³ The Hon. Diana Bryant, AO, Chief Justice. Submission to the Senate Community Affairs Committee Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia. 2013 Feb 22. Available from: <http://www.aph.gov.au/DocumentStore.ashx?id=75906320-b2bb-43dd-9d0a-3fe58a7d93f9&subId=16140>

to merge the Family Court and the Federal Circuit Court.⁷⁴ In our view, this merger will not itself address the issues that we raise in our Shadow Report, and any observations by the Committee would be timely and helpful for the review of the family law system.

8.1 *Welfare of a Child A (1993)*

In 2013, the Hon. Diana Bryant AO made a submission to the Senate inquiry on involuntary or coerced sterilisation. In her submission, the former Chief Justice cited the case of *Welfare of a Child A* [1993] FamCA 68.⁷⁵ The adolescent boy in this case was diagnosed with congenital adrenal hyperplasia (CAH) at birth (at [5]), and presented as suicidal.

Legally registered male with a male birth certificate (at [7]), the child was described clinically as a ‘genetic female’ due to XX sex chromosomes, and subjected to early ‘feminising’ surgeries (at [10]).

Furtado and others have stated in a 2012 clinical review that generally ‘between 8.5–20% of individuals with DSDs’ will experience distress associated with their gender assignment, including one in ten individuals with CAH. They state nonetheless that: ‘Early surgery seems to be a safe option for most’ children with that diagnosis.⁷⁶ Even discounting known consequences for sexual function and sensation (not mentioned in this clinical review), there is no method of distinguishing those whose gender identity will change from those whose identity will not. Such surgeries remain the standard protocol for children with CAH.

Justice Mushin, now an adjunct professor of law at Monash University, Victoria, did not question these ‘feminising’ surgeries in his judgment but was, instead, critical of the parents, blaming the mother for the child’s male gender identity. He stated:

9. The application which is made by the mother seeks authorisation from the court that A be permitted to undergo bilateral mastectomies, a hysterectomy and oophorectomy...

10. The background for this is well expressed by the surgeon. His report, to the extent that it is relevant, is in the following terms:

Following investigation after birth, this child was correctly assessed as being a genetic female with an extreme degree of masculinization. The degree of masculinization is variable and depends on the severity of the original abnormality in the adrenal gland. In some children this is mild and in others it is severe. However, in all cases it would be standard medical practise (sic) to raise the child as a female with a potential for normal female fertility. The genitalia are therefore operated on in the postnatal period to make them

⁷⁴ Wangmann, Jane, and Miranda Kaye. ‘A New Family “super Court” May Not Save Time or Result in Better Judgments’. *The Conversation*, 31 May 2018. <http://theconversation.com/a-new-family-super-court-may-not-save-time-or-result-in-better-judgments-97454>.

⁷⁵ *Welfare of a Child A* [1993] FamCA 68; (1993) FLC 92-402 16 Fam Lr 715 Children (30 June 1993).

⁷⁶ Furtado PS, Moraes F, Lago R, Barros LO, Toralles MB, Barroso U. Gender dysphoria associated with disorders of sex development. *Nature Reviews Urology*. 2012;9:620–7.

feminine in appearance. This advise (sic) and treatment was carried out in (A's) early years and she had genital reconstruction to give her a feminine appearance. She was also given cortisone hormone treatment to replace the absent hormone and prevent any further masculine hormones being produced by the abnormal adrenal gland...

12. Further in that report the endocrinologist states:

As (A's) endocrinologist, I consider her to be completely male in her outlook due to the prenatal and postnatal exposure to excessive levels of adrenal androgen. I do not believe that this situation is reversible...

13. I am critical of both the parents, and particularly the mother, that the treatment recommended by the doctors at the time of the A's birth was not pursued. It appears on the basis of the material which is available to me that had that treatment been undertaken it may well have been possible to avoid the appalling situation which has now arisen and in respect of which I am asked to make this decision.

We note that the difficult situation presented in the judgment would not have been appalling at all, had the boy not been subjected to unnecessary early surgeries, yet the judge did not comment at all on their necessity or the appalling consequences for this child. All subsequent surgeries were in line with the child's legal sex, original sex assignment and gender identity, and were sought to support his male sex of living.

In most scenarios, the early 'feminising' surgeries on children with XX sex chromosomes (a 'genetic female') would be described as female genital mutilation. If child A was to be regarded as a girl, as clinicians did, then policies prohibiting female genital mutilation should have applied. However, we note a specific exemption in Australian policy frameworks that (perhaps inadvertently) permit medical interventions despite lack of evidence of necessity.

The judge was egregious in criticism of the parents. As identified by the Committee on Bioethics of the Council of Europe, there is no evidentiary basis to claim that medical interventions or parents can influence gender development.³⁹

In her comments on the case in 2013, the Chief Justice of the Family Court stated that 'the trial judge found that A had "an overwhelming expectation and desire to have the operations referred to so that he may assume what he regards as being his right and expectation, that is to become a male in all possible respects".'⁷³ That is, the Chief Justice of the Family Court also chose not to comment on the appropriateness, indications, necessity or evidence for earlier 'feminising' surgeries.

8.2 *Re: Carla (Medical procedure) (2016)*

The case of *Re: Carla (Medical procedure)* [2016] FamCA 7 was initiated by the parents of a child pseudonymously named Carla and adjudicated in the State of Queensland. An anonymous State government department was appointed as a friend of the court.⁷⁷

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, described, in more particular medical terms, as 17 beta hydroxysteroid dehydrogenase 3 deficiency’ (at [1]), with XY sex chromosomes, testes, and predominantly female genitalia.

Justice Forrest stated that ‘the proposed surgery for Carla involving the bilateral removal of her gonads (“gonadectomy”) ... may be authorised by either of Carla’s parents’. This has taken similar cases out of Court jurisdiction.

Justice Forrest argued that the gonadectomy (sterilisation) was justifiable on the basis of a potential cancer risk, stating that ‘the Consensus Statement for Management of Disorders of Sexual Development puts the risk of germ cell malignancy at 28% ... said to be an intermediate level of risk of malignancy’ (at [19]) and it was ‘...virtually impossible to regularly monitor them for the presence of tumours’ (at [20]). There is no evidence for this. As previously mentioned, a German multidisciplinary team advised Amnesty International this year that, cancer risk can be monitored effectively even for high risk groups.⁴⁶

Indeed, the medical journal article referenced in the judgment was consciously misquoted, seemingly to avoid mentioning the word intersex, and the actual ‘Consensus statement on management of intersex disorders’, citing a risk of 28%, itself states that clinicians should ‘monitor’ gonads in children with 17 beta hydroxysteroid dehydrogenase 3 deficiency (17 β HSD).⁷⁸ In other words, the current international position recommends against surgery in favour of a more cautious monitoring. A more recent clinical review published in 2010 reduces estimates of risk levels to 17%.⁷⁹ According to clinical literature, the retention and monitoring of gonads should have been unambiguously supported. This is in line with best practice, as evidenced by the German team that advised Amnesty International. The medical evidence cited in the judgment identifies cancer risk as the therapeutic justification for sterilisation, although a gonadectomy in those circumstances is not consistent with established best practice even within a conservative medicalised paradigm.

Given the length and detail of the supporting information, it appears that gender stereotyping substantively comprises the rationale for sterilisation, mostly on the basis of parental reporting and clinical affidavits:

⁷⁷ *Re: Carla (Medical procedure)* [2016] FamCA 7 (20 January 2016)

⁷⁸ 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.

⁷⁹ 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.

15. In 2014, when Carla was almost four years of age, she was reviewed by Dr S who formed the opinion that Carla had developed a female gender identity and identified as a female and that this was unlikely to change in the future. Dr S formed this opinion based on the following observations:

- 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*
- 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])*

The reliance on such crude gender stereotyping illustrates clearly our concerns with current medical practices, and is disturbing. Furthermore, these were third party report; the Court is not required to give a child an opportunity to express their own views.⁸⁰ Carla is not yet an independent agent and presumably the gender performance described in the above extract reflects the parents' choices and actions rather than (or at least as much as) the preferences of Carla herself. Given the absence of clear medical evidence in support of Carla's sterilisation, her current gender presentation and future gender identity are irrelevant. Similarly, no-one can be confident of her future gender identity and sexual orientation; these are simply unknown. However, 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.⁸¹

The medical literature on this issue is clear: many children with Carla's diagnosis undergo spontaneous change of gender identity at puberty. The conclusion of the psychiatric expert expressing confidence that Carla's gender identity was stable at age 3/almost 4 (at[15]) is directly at odds with the 'well known' experience evidenced in the clinical literature.

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

⁸⁰ Commonwealth of Australia. Family Law Act 1975 - Sect 60CD How the views of a child are expressed [Internet]. Available from: http://www8.austlii.edu.au/cgi-bin/viewdoc/au/legis/cth/consol_act/fla1975114/s60cd.html

⁸¹ Hewitt JK, Warne GL. Management of disorders of sex development. Pediatric Health. 2009;3(1):51–65.

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

This action appears to infringe articles 14 and 24 of the ICCPR,⁸² guaranteeing equality before the law and protection without discrimination, and article 12 of the Convention on the Rights of Persons with Disabilities guaranteeing equal recognition before the law and the exercise of legal capacity.⁸³ Despite this justification for early sterilisation, we note that Justice Forrest made no such claim about trauma arising from a different possible medical intervention:

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

This focus on the suitability of Carla's body for heterosexual intercourse reflects heteronormative assumptions and values; and approach validated in a Victorian 2010 ethical framework that enumerated marriage prospects amongst rationales for medical intervention.

Despite rhetoric to the effect that the multidisciplinary team and the parents had patiently deferred any irrevocable intervention until Carla was developmentally able to express a fixed gender identity, the fact that feminising genital surgeries had already been performed well before the hearing indicates that the parents and medical team were not content to wait until Carla had formed a fixed gender identity before commencing interventions that explicitly and irreversibly shaped her body towards a 'feminine' appearance. The applicants and the expert witnesses had become irrevocably invested in Carla being assigned and physically shaped as a female before these proceedings had commenced.

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 (at [16])

These abhorrent, irreversible, non-therapeutic and invasive interventions were disclosed as incidental to a case brought to sterilise the child. This raises concern about a conflict of interest, where both clinicians and parents are invested in the success of early surgical interventions.⁸⁴

⁸² Office of the High Commissioner for Human Rights. International Covenant on Civil and Political Rights. 1966.

⁸³ United Nations. Convention on the Rights of Persons with Disabilities [Internet]. Geneva: United Nations; [cited 2015 Mar 23]. Available from:

<http://www.un.org/disabilities/convention/conventionfull.shtml>

⁸⁴ An early case note can be found at: Carpenter M. The Family Court case Re: Carla (Medical procedure) [2016] FamCA 7 [Internet]. Intersex Human Rights Australia. 2016 [cited 2016 Dec 7]. Available from: <https://ihra.org.au/31036/re-carla-family-court/>

The clitoral recession and labioplasty performed on Carla fit the criteria for ‘vulvoplasties’, and the case of Re: Carla fits the criteria for so-called “congenital malformations”. As described above, we note that the 2014 Department of Health Medicare Benefits Schedule Review on ‘vulvoplasties’ identified 371 Medicare-funded vulvoplasties for so-called ‘congenital malformations’ during the period 2007/8 to 2011/2; an average of 74.2 per year; and a similar number of ‘vulvoplasties’ are performed on children aged under 15. Australia, in common with many other countries, maintains a legal prohibition on Female Genital Mutilation including all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for ‘non-medical reasons’.⁶⁸ Cultural standards relating to genital appearance are not recognised as valid medical reasons for FGM. Further, the World Health Organization and other bodies recognize that medicalization, including as a form of harm reduction, does not justify FGM.

The judge also noted that:

the parents and medical experts agree that it is in the best interests of the child to undergo the [sterilisation] procedure

At the end of the hearing, with the approval of the applicants, I made the orders that the parents sought, satisfied that they were in the best interests of Carla (at [7])

The Committee on the Rights of the Child General Comment 14 ‘on the right of the child to have his or her best interests taken as a primary consideration’ states:

34. The flexibility of the concept of the child’s best interests allows it to be responsive to the situation of individual children and to evolve knowledge about child development. However, it may also leave room for manipulation; the concept of the child’s best interests has been abused by Governments and other State authorities to justify racist policies⁸⁵

Committee on the Rights of the Child General Comment 13 on ‘Article 19: The right of the child to freedom from all forms of violence’ states that interpretations of best interests ‘cannot be used to justify practices ... which conflict with the child’s human dignity and right to physical integrity’:

54. Article 3 (Best interests of the child): The Committee emphasizes that the interpretation of a child’s best interests must be consistent with the whole Convention, including the obligation to protect children from all forms of violence. It cannot be used to justify practices, including corporal punishment and other forms of cruel or degrading punishment, which conflict with the child’s human dignity and right to physical integrity. An adult’s judgment of a

⁸⁵ Committee on the Rights of the Child. General Comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1). 2013. Report No.: CRC/C/GC/14, para. 34. Available from: <http://undocs.org/CRC/C/GC/14>

*child's best interests cannot override the obligation to respect all the child's rights under the Convention.*⁸⁶

Unnecessary medical interventions such as genital appearance 'enhancing' interventions, should not be regarded as therapeutic. The child's sterilisation should not have been approved on the basis of the evidence and reasoning presented in the judgment. Further, the decision to enable parental choice on sterilisation has taken future sterilisation cases out of Court jurisdiction, for the 'potential benefit of any parents, like them, who might find themselves in these very same factual circumstances in the future' (at [8]). The far-reaching consequences of this decision are alarming given the evidence of human rights breaches.

It is not clear that either Carla's parents or the Court were provided with accurate and comprehensive information or medical evidence supporting the interventions on the child. It appears that the family have had no access to independent peer support.

Overall, this 2016 Family Court of Australia case is deeply disturbing, exemplifying the way that the human rights of intersex children are violated with inadequate evidence for social and cosmetic purposes.

IHRA board members and many other individuals have personally experienced similar interventions, with negative personal and familial consequences.⁸⁷ There are multiple publicly available documents attesting to the experiences of intersex people who have been subjected to unnecessary medical interventions such as these. It is a telling criticism that Justice Forrest seems oblivious to the strong and diverse challenges to the medicalised approach adopted by the team of experts responsible for Carla's care, despite the comprehensive outline of these challenges in the Report of the Senate Committee published in 2013.

The case also provides evidence of State complacency and complicity. In 2012, the local Department of Communities in Queensland wrote that:

⁸⁶ Committee on the Rights of the Child. General Comment 13: Article 19: The right of the child to freedom from all forms of violence. 2011. Report No.: CRC/C/GC/13, para. 54. Available from: <http://undocs.org/CRC/C/GC/13>

⁸⁷ Copland S. The medical community's approach to intersex people is still primarily focused on "normalising" surgeries [Internet]. SBS. 2016 [cited 2016 Dec 15]. Available from: <http://www.sbs.com.au/topics/sexuality/agenda/article/2016/12/15/medical-community-approach-intersex-people-still-primarily-focused-normalising>

Overington C. Family Court backs parents on removal of gonads from intersex child. The Australian [Internet]. 2016 Dec 7 [cited 2016 Dec 7]; Available from: <http://www.theaustralian.com.au/news/health-science/family-court-backs-parents-on-removal-of-gonads-from-intersex-child/news-story/60df936c557e2e21707eb198f1300276>

Overington C. Carla's case ignites firestorm among intersex community on need for surgery. The Australian [Internet]. 2016 Dec 8 [cited 2016 Dec 8]; Available from: <http://www.theaustralian.com.au/national-affairs/health/carlas-case-ignites-firestorm-among-intersex-community-on-need-for-surgery/news-story/7b1d478b8c606eaa611471f70c458df0>

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.⁸⁸

A 2016 “Sexual Health Strategy” published by Queensland Department of Health makes no statements about the sexual health implications of medical interventions on intersex infants, children or adolescents. It states:

Parents and carers of children born with an intersex condition which may require surgical intervention must be fully informed about the intersex condition specific to their child and have all available treatment options explained to them. Informed consent from legal guardians is also essential if treatment is to be undertaken on children and young people later in life for normalisation and gender affirmation. Medical management of children with intersex variation [sic] may be complex and ongoing interventions may include surgery and lifelong hormone therapy... Medical treatment is sometimes necessary to help development proceed as normally as possible and for some conditions, surgical treatment may be recommended.⁸⁹

These 2016 descriptions and justifications for early medical interventions are unsupported by evidence, and fail to acknowledge the human rights and ethical implications of medical interventions, including when and where surgery may be appropriate, or when and where parental consent is adequate or permissible. The statement contains clear and repeated presumptions favouring so-called “normalisation” and “normal development”. The 2016 document was published in advance of press reporting of the case *Re: Carla (Medical procedure)*, in December 2016.⁸⁷

8.3 *Re: Lesley (Special Medical Procedure) (2008)*

In the Family Court case *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226, a judge approved the sterilisation of a young child with the same intersex variation as the child in *Re: Carla* (i.e. 17 β -HSD3).⁹⁰ The facts of this case are substantively the same as those in *Re: Carla*, albeit that clinical rationales and any genital surgeries were not disclosed in the same manner, and the Court did not take subsequent approval processes out of Court jurisdiction. Indeed, the judge in *Re: Carla* appeared to comment in detail on the circumstances of Carla specifically in response to an invitation to consider whether or not judicial approval was

⁸⁸ Department of Communities. ‘Engaging Queenslanders: A Guide to Working with Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Communities’, January 2012.

⁸⁹ Department of Health, and Queensland. ‘Health Strategies - Queensland Sexual Health Strategy (Draft for Consultation) - Publications | Queensland Government’, 25 May 2016.

<https://publications.qld.gov.au/dataset/health-strategies/resource/e45a2284-d20d-431d-84bd-9d9111cb77a4>.

⁹⁰ *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226

required for the sterilisation of Carla. Risks of gonadal tumour were stated to be ‘significant’ (at [40]). While a later re-evaluation of risks had not yet been published,⁷⁹ clinical guidance recommending the monitoring of gonads had been published.⁷⁸ There was no clinical consensus supporting removal of gonads.

Sterilisation was intended to prevent the child’s body from virilising at puberty. According to a submission by counsel, the alternative to sterilisation included (at [39]) to:

- (a) *take no action and allow [Lesley] to virilise and make a determination about her gender later*

That is, sterilisation was not predicated on clinical urgency regarding cancer risk, but instead to surgically reinforce a female gender assignment and pre-empt later self-determination. The alternative option of puberty blockers to support later self-determination appears not to have been examined.

8.4 Re: Kaitlin (2017)

The case of *Re: Kaitlin* [2017] FamCA 83, was taken by the parents of a child pseudonymously named Kaitlin. Kaitlin was born in 2000 with a pituitary impairment.⁹¹

An intersex and transgender child, ‘she has not undergone stage one treatment, which comprises hormone blocking, because she suffers from hypopituitarism, in consequence of which her body is incapable of naturally producing testosterone, or indeed, many other hormones’ (at [2]).

Indeed, Kaitlin ‘identified as female from a very early age. She has always resented being characterised as male’ (at [5]).

Unlike endosex (non-intersex) transgender children in Australia, where such interventions require Family Court approval: ‘At about age 12 or 13 she was prescribed testosterone in order to commence puberty’ (at [6]). This was an inappropriate, forced intervention.

When Kaitlin understood the nature of the hormone treatment, she was, because of her gender identity, understandably non-compliant with that testosterone treatment. Justice Tree approved ‘cross-sex’ hormone treatment.

In our view, Kaitlin should never have been prescribed testosterone in the first place. The adolescent child should have been consulted about her treatment, and her voice in relation to her treatment should have been respected. The Court’s failure to note and comment on the failure of the parents and medical team to obtain appropriate consent to the hormone therapy instituted when Kaitlin was age 12 is unfortunate.

⁹¹ *Re: Kaitlin* [2017] FamCA 83.

8.5 Commentary

In her 2013 comments to the Senate inquiry on involuntary or coerced sterilisation, the Hon Diana Bryant, former Chief Justice of the Family Court, stated that:

I appreciate that the Committee may be contemplating scenarios whereby permission is sought to perform surgery on a young child to give them the appearance of one sex or another, without the child being of sufficient age and maturity to express a view as to the procedure. I am not aware though of judgment having been delivered in any such case before the Family Court.⁷³

IHRA has seen no evidence that Court oversight has ever been sought for genital so-called ‘normalising’ surgeries. Clearly, however, such interventions occur without clinicians, governments, or parents seeking Court oversight, and the former Chief Justice and other Family Court justices have had ample opportunities to become aware of this failure of process and to comment on it. Such interventions are documented in medical histories in the 1993 case *Welfare of a Child A* cited by the Chief Justice in her comments to the Senate, and in the 2016 case *Re: Carla (Medical procedure)*.

It is also clear that, where such interventions are documented in the medical histories of children whose cases appear before the Court, no comment has ever been made by the Court questioning the suitability, appropriateness, indications, rationales, outcomes, or evidence for such prior medical interventions; or, in the case of *Re: Carla (Medical procedure)*, such interventions are described as having ‘enhanced’ genital appearance. This is gravely disturbing.

Aileen Kennedy (now a director of IHRA) describes the situation as one of ‘complicity between the medical and the legal construction of variations of sex development as pathological disorders in urgent need of correction’ where a ‘tension between the medical and judicial responses to variations of sex development has disappeared’.⁹²

The Australian healthcare system appears to regard such interventions as unambiguously therapeutic due to parental distress and potential psychosocial stigma, even when they take place on healthy intersex bodies, or where clinical evidence supports monitoring gonads, even though such interventions contravene human rights norms established by multiple UN Conventions and the conclusions of a Senate inquiry.

⁹² Kennedy A. Fixed at Birth: Medical and Legal Erasures of Intersex Variations. UNSW Law Journal. 2016;39(2):813–42.

9 Testimonies

Board members and members of Intersex Human Rights Australia have discussed aspects of their medical histories in interviews with media and in other published testimony.

IHRA member Alex David and AISSGA president/IHRA member Bonnie Hart were interviewed by the broadcaster SBS in late 2016, regarding the Family Court case *Re: Carla (Medical procedure)*. Alex stated:

SBS spoke to Alex David, who had her first gender assignment surgery when she was a baby, with doctors removing her internal gonads. At the same time, Alex says, doctors also wanted to “chop off all her sensitive bits”, but her mother stopped them.

“The next surgery I had was when I was seven years old, and that was to tuck everything in and essentially make a vagina, but a man-made one,” Alex explains.

It was not until Alex was seventeen she found out she had an intersex variation. This created significant mental anguish, with Alex being forced to find ways to deal with how she had been treated, commenting that sometimes she describes her surgeries impersonally, because that’s how her brain “copes with it”.⁹¹

Bonnie stated to SBS:

As a child, Bonnie had multiple medical interventions, including surgery to remove her testis, hormone therapy and a process of vaginal dilation that started at age thirteen. Bonnie said this had long term impacts, noting that although she had signed her consent for the procedures, she “didn’t consent for the life that [she] ended up having as a result of that”.

“I have health complications now that are the direct effect of the treatments I received because of my intersex variation,” she continued. “I have to take hormone replacement therapies and then there’s indirect mental health stuff that has gone along with it.”

Bonnie says she felt like she “was in heteronormative sexual training from a really early age, too young.”

She continues: “I think a lot of these surgeries happen in order to justify social stigma or as the result of a fear of difference. There’s social reasons why these surgeries happen. And they don’t offer social remedies for them, they offer surgical remedies. That’s not fair on the intersex person. That’s putting all the responsibility back on that individual.”⁸⁷

In 2014, Shon Klose was interviewed by the Australian Broadcasting Corporation:

I'd finished school and applied for nursing and as part of that process I had to have a medical examination. During the examination the doctor asked me about my menstrual cycle and I'd never had a menstrual cycle... During the examination it was apparent that I was actually quite different. I have a variation known as Mayer-Rokitansky-Kuster-Hauser syndrome, or vaginal agenesis. I was born with no internal reproductive system.

It was a huge shock. I think I became quite atrophied, and I think that was mainly because of the specialist's reaction to me. He didn't really know what to say, he had not come across someone like me before. When he did the examination his response was 'Oh my god, you don't have a vagina'. He took me into another room and did an ultrasound and said 'Oh my god, you haven't got a uterus, I can't see any ovaries and you've only got one kidney by the look of it, you'll have to have surgery, you'll have to have this corrected'.

There was pressure from the doctors and pressure from my family to have surgery and that surgery was basically a vaginoplasty. I went through a huge amount of trauma. I wasn't offered any counselling, there was no support, no information.

A vaginoplasty is an incision...there was no opening there at all, it was just solid muscle, so I had to have a glass tube sewn inside me for 14 days. I had a catheter and I couldn't sit or stand, it was so extremely painful. I had 75mg of pethidine every four hours for two weeks.

One day I was lying there and the surgeon came around with a whole lot of interns and drew the curtain. He asked me to spread my legs so he could show them the success of the surgery. He hadn't talked to me, hadn't discussed it with me, hadn't given me any heads up that he would be coming around.

I was supposed to dilate with a glass tube every day for the rest of my life to keep the opening big enough for penetration, but I came out of hospital and tried to do this and it was so excruciatingly painful that I took the glass tube and I smashed it on the ground and I've never dilated again since.⁹³

⁹³ Sleath E. I am intersex: Shon Klose's story. ABC Alice Springs [Internet]. 2014 Dec 2 [cited 2014 Dec 2]; Available from: <http://www.abc.net.au/local/stories/2014/12/01/4140196.htm>