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For intersex human rights, information, and peer support

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Shadow Report submission to the Committee on the Rights of Persons with Disabilities on the situation of intersex people in Australia

1 Submitting organisations

This Shadow Report has been written and submitted by **Organisation Intersex International Australia Limited** (“OII Australia”), a national organisation run by and for people born with intersex variations. OII Australia promotes the human rights and bodily autonomy of intersex people in Australia, and provides information, education and peer support. OII Australia is a not-for-profit company, with Public Benevolent Institution (charitable) status.

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This submission is endorsed by:

The **Androgen Insensitivity Syndrome Support Group Australia** (“AISSGA”), a peer support, information and advocacy group by and for people affected by androgen insensitivity syndrome (“AIS”) and/or related intersex variations and variations of sex characteristics, and their families.

The **Disabled People’s Organisations Australia** (“DPO Australia”), a national coalition of Disabled People’s Organisations, which are run by and for people with disability and grounded in a normative human rights framework.

The **National LGBTI Health Alliance**, the national peak health organisation in Australia for organisations and individuals that provide health-related programs, services and research focused on lesbian, gay, bisexual, transgender, and intersex people (LGBTI) and other sexuality, gender, and bodily diverse people and communities.

People with Disability Australia (“PWDA”), a national disability rights and advocacy organisation, and member of DPO Australia. PWDA’s primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also have a large associate membership.

2 Summary

The Convention on the Rights of Persons with Disabilities seeks to guarantee equality before the law (**article 5**); ensure that children have full enjoyment “of all human rights and fundamental freedoms”, that “the best interests of the child shall be a primary consideration” and that children have the right to express their views in accordance with their age and maturity (**article 7**); exercise of legal capacity and equal recognition (**article 12**); access to justice (**article 13**); that persons may not be subjected to medical or scientific experimentation, torture, or cruel, inhuman or degrading treatment (**article 15**); that every “person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others” (**article 17**); respect for privacy (**article 22**); and the right to the enjoyment of the highest attainable standard of health without discrimination (**article 25**).¹

A pattern of human rights abuses on infants, children and adolescents with intersex traits 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 unnecessary sterilisation of a 5-year old child with the approval of the Family Court of Australia, and incidental disclosure in that child’s medical history of a clitorrectomy and labiaplasty described by the judge, in 2016, as having “enhanced the appearance” of her genitalia. The child in *Re: Carla (Medical procedure)* was described as having a “sexual development disorder”,² more usually described in clinical settings as a “disorder of sex development”. The framing of intersex variations using such terms, despite often only cosmetic (appearance “enhancing”) purposes for medical interventions, makes them a matter of concern to the Committee on the Rights of Persons with Disabilities.

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 variations.³

In May 2017, in response to questioning by the UN Committee on Economic Social and Cultural Rights, it appears that the Australian government has rejected the recommendations of a 2013 Senate Community Affairs References Committee inquiry into the involuntary or coerced sterilisation of people with disabilities, and of intersex people.⁴ It appears that the government may be considering the implications of recent Family Court cases,⁵ however, these are not new concerns. We regard this approach as inadequate, and part of a continuing pattern of deferral and delay without action.

¹ 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>

² 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>

³ Carpenter M. The human rights of intersex people: addressing harmful practices and rhetoric of change. *Reproductive Health Matters*. 2016;24(47):74–84.

⁴ <https://twitter.com/deanpwda/status/869848554617151488>

⁵ <https://twitter.com/deanpwda/status/869850421497655296>

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 UN Committee on the Rights of Persons with Disabilities acknowledges that platform, the Darlington Statement,⁶ and asks the government of Australia:

1. How will the government ensure that infants, children and adolescents are not subjected to unnecessary medical or surgical treatment during infancy or childhood, guaranteeing the rights of children to bodily integrity, autonomy and self-determination. In particular, how will the government 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. Will the government criminalize non-emergency/deferrable medical interventions medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent of the recipient?
3. What measures will the government undertake to 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. How will the government 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. How will the government provide redress to people who have undergone unwanted sterilisations and other medical interventions to “normalise” sex characteristics?
6. Will the government 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?
7. How will the government 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? How will the government ensure that pros and cons for and against medical treatment will be properly ventilated and considered, including the lifetime health, legal, ethical, sexual and human rights implications?
8. How will the government ensure that medical and psychological professionals, and parents, are educated on bodily and sexual diversity and on human rights norms,

⁶ 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 [Internet]. 2017 [cited 2017 Mar 10]. Available from: <https://oii.org.au/darlington-statement/>

and on the consequences of unnecessary interventions for children born with non-normative sex characteristics?

9. How will the government ensure that adults with intersex variations are able to freely access medical interventions to manage sex characteristics, including unwanted iatrogenic changes to sex characteristics.

4 Contents

1	Submitting organisations.....	1
2	Summary	2
3	Recommendations.....	3
4	Contents	5
5	Who are intersex people?	6
6	Human rights and intersex people	7
7	The Australian policy context	13
8	The Family Court of Australia	17
8.1	Welfare of a Child A (1993)	17
8.2	Re: Carla (Medical procedure) (2016)	19
8.3	Re: Kaitlin (2017)	22
8.4	Commentary.....	22
9	Victoria	24
10	Australian Capital Territory	30
11	New South Wales	32
12	Queensland.....	33
13	South Australia	35
14	Other States and Territories	35
15	Testimonies	36
16	Citation	41

5 Who are intersex people?

OII Australia refers to intersex people in this document in line with the definition used by the UN Office of the High Commissioner for Human Rights:

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. For some intersex people these traits are apparent at birth, while for others they emerge later in life, often at puberty.⁷

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 a spectrum or umbrella term, rather than a single category. At least 30 or 40 different variations are known to science;⁸ 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,X0 (often diagnosed as Turner syndrome). Many persons do not have clear genetic diagnoses.⁸ Some common intersex variations are diagnosed prenatally.⁹

⁷ 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>

⁸ 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

⁹ 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

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).¹⁰ 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.*¹¹

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 asked Germany to implement 2011 recommendations on the rights of intersex people made by the Committee Against Torture (“CAT”),¹² including proper informed consent, investigation and redress, and provider training.¹³ We note that action remains awaited in Germany, and the Committee on the Elimination of All Forms of Discrimination against Women (“CEDAW”) made similar recommendations in 2017.¹⁴

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.”¹⁵ The Committee on the Rights of the Child (“CRC”) has described such interventions in similar terms,¹⁶ including in relation to practices by our neighbour, New Zealand.¹⁷

The Convention on the Rights of Persons with Disabilities seeks to guarantee equality before the law (article 5); ensure that children have full enjoyment “of all human rights and fundamental freedoms”, that “the best interests of the child shall be a primary consideration” and that children have the right to express their views in accordance with their age and maturity (article 7); access to justice (article 13); that persons may not be

¹⁰ 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

¹¹ 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>

¹² CAT/C/DEU/CO/5, 12 December 2011

¹³ CRPD/C/DEU/CO/1, 17 April 2015

¹⁴ CEDAW/C/DEU/CO/7-8, 3 March 2017

¹⁵ A.HRC.22.53. 2013, 1 February 2013

¹⁶ For example, in CRC/C/GBR/CO/5, 3 June 2016

¹⁷ CRC/C/NZL/CO/5, 7 October 2016

subjected to medical or scientific experimentation, torture, or cruel, inhuman or degrading treatment (article 15); that every “person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others” (article 17); respect for privacy (article 22); and the right to the enjoyment of the highest attainable standard of health without discrimination (article 25).¹

General Comment 3 (2016) regards forced or coercive sterilisation and “surgery or treatment performed on intersex children without their informed consent” as “cruel, inhuman or degrading treatment or punishment and as breaching a number of international human rights treaties”.¹⁸ General Comment 3 also recognises that these may be facilitated by restrictions on legal capacity (article 12).¹⁸ In our view, poor quality, negative, inaccurate and selective information provision to parents, and unnecessarily early interventions on intersex children, both restrict legal capacity.

The subjects of medical treatments are infants and children, but interventions frequently aim to tackle parental distress. While detailing poor outcomes from feminising surgeries, for example, Thomas asks “would parents be prepared to contemplate raising their daughter with uncorrected virilization?”.¹⁹ The concept of correction is itself predicated on an error to be fixed.

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”.²⁰

Parents and clinicians may make decisions based upon delivery room distress,⁶⁵ 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.*²¹

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

¹⁸ CRPD/C/GC/3, 25 November 2016

¹⁹ Thomas DFM. Gender assignment: background and current controversies. *BJU International*. 2004;93 Supplement 3:47–50.

²⁰ 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.

²¹ Greenberg JA. *Intersexuality and the Law: Why Sex Matters*. New York: New York University Press; 2012.

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”.²² However, Liao et al report in The BMJ that “parental regret can be high”,²³ and parents “may not realise that they are de facto opting for experimental surgery on their children”,²³ with no credible 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.*²⁴

In 2015, the Council of Europe’s Human Rights Commissioner recognised a right to *not* undergo sex assignment treatment; we believe this recognition has global relevance.²⁵

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:

*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.*²⁶

In 2017, a first “feasibility study” on deferral of genital surgeries for ambiguous genitalia in seven children with 21-hydroxylase deficiency in France was published in a clinical journal. The authors acknowledged “Multiple scientific voices” joining advocates to question the

²² Dayner JE, Lee PA, Houk CP. Medical Treatment of Intersex: Parental Perspectives. *Journal of Urology*. 2004;172(4):1762–5.

²³ Liao L-M, Wood D, Creighton SM. Parental choice on normalising cosmetic genital surgery. *BMJ*. 2015;351:h5124.

²⁴ 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>

²⁵ Council of Europe, Commissioner for Human Rights. Human rights and intersex people, Issue Paper. Strasbourg; 2015.

²⁶ 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.

purported necessity of early genital surgery, as well as poor post-surgical sensitivity and poor long-term cosmetic outcomes. They stated that:

Despite concerns, inertia has perpetuated the practice of early genital surgery into the present, and, to date, there have been no series of patients left unoperated until adolescence or adulthood so as to form a basis for comparison.²⁷

This absence of intact individuals is not true of many middle and low income countries, such as Mexico.²⁸ While the feasibility study still had “normalising” intent and genital examinations, they concluded that, in their population, “deferring genital operation is acceptable among patients and families”.²⁷ It is concerning that an initial clinical study on deferral of surgery has been published for the first time only this year.

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 stating 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 excretion²⁹

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*

²⁷ Bougnères P, Bouvattier C, Cartigny M, Michala L. Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: a feasibility study. *International Journal of Pediatric Endocrinology*.2017(3).

²⁸ Inter L. The situation of the intersex community in Mexico [Internet]. Intersex Day. 2016 [cited 2016 Oct 26]. Available from: <http://intersexday.org/en/situation-mexico/>

²⁹ 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 medical literature has not addressed the implications of whether clinicians and parents have a right to assign these identities surgically and irreversibly on children*²⁹

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 appearance*²⁹

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; all surgeries affect physical sensitivity.³⁰

Furthermore, the Committee on Bioethics report states that the lack of scientific evidence in support of medical interventions means that the right to freedom from experimentation is adversely impacted as:

*children continue to undergo unproven treatments without proof of their therapeutic character*²⁹

We also note similar concern by Kirsten Sandberg, former chair of the Committee on the Rights of the Child, that “parents have no right to consent to” sex assignment or “normalising” interventions as “treatment is not medically necessary” and can be deferred; “the matter is so personal and serious that treatment should not be carried out without the child’s consent.”³¹

Such harmful practices are increasingly condemned as Intersex Genital Mutilations (“IGM”).³²

³⁰ 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>

³¹ Sandberg K. The Rights of LGBTI Children under the Convention on the Rights of the Child. *Nordic Journal of Human Rights*. 2015;33(4):337–52.

³² Zwischengeschlecht.org. Intersex Genital Mutilations Human Rights Violations Of Children With Variations Of Sex Anatomy: NGO Report to the 2nd, 3rd and 4th Periodic Report of Switzerland on the Convention on the Rights of the Child (CRC) [Internet]. Zurich; 2014 Mar [cited 2014 Jun 1]. Available from: http://intersex.shadowreport.org/public/2014-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

United Nations Office at Geneva. Committee on the Elimination of Discrimination against Women considers the reports of Germany [Internet]. 2017 [cited 2017 Feb 23]. Available from:

[http://www.unog.ch/unog/website/news_media.nsf/\(httpNewsByYear_en\)/9F8ED815BA5A5E23C12580CE005BBD79?OpenDocument](http://www.unog.ch/unog/website/news_media.nsf/(httpNewsByYear_en)/9F8ED815BA5A5E23C12580CE005BBD79?OpenDocument)

In response to these concerns, as described by Morgan Carpenter: “A global and decentralised intersex movement pursues simple core goals: the rights to bodily autonomy and self-determination, and an end to stigmatization.”³

In 2015, Malta became the first country to prohibit unnecessary modifications to the sex characteristics of children, with a prohibition on medical interventions with social rationales.³³

In relation to reparations, Daniela Truffer and Marcus Bauer of Zwischengeschlecht.org have observed that no persons exposed to coercive medical “normalising” interventions during childhood have yet succeeded in court action.³⁴ This appears to be due to both statutes of limitations and clinical claims of consensus regarding treatment and indications.³

CRC/C/ZAF/CO/2, 27 October 2016

³³ Government of Malta. Gender Identity, Gender Expression and Sex Characteristics Act: Final version [Internet]. 2015. Available from:

<http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1>

³⁴ Zwischengeschlecht.org, IntersexUK, OII-UK, The UK Intersex Association. Intersex Genital Mutilations Human Rights Violations of Children with Variations of Sex Anatomy: NGO Report to the 5th Periodic Report of the United Kingdom on the Convention on the Rights of the Child (CRC) [Internet]. Zurich; Apr 2016 [cited 23 May 2016]. Available from:

http://intersex.shadowreport.org/public/2016-CRC-UK-NGO-Zwischengeschlecht-Intersex-IGM_v2.pdf

7 The Australian policy context

In 2013, a new attribute of “intersex status” was added to federal anti-discrimination law,³⁵ 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,³⁶ understood to be reflected in a public submission to the inquiry by the Australasian Paediatric Endocrine Group (“APEG”). It stated 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.*³⁷

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.³⁸

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. It 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:

³⁵ ComLaw. Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013 [Internet]. Available from: <http://www.comlaw.gov.au/Details/C2013A00098/>

³⁶ 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

³⁷ 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=afe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>

³⁸ Department of Health & Community Services v JWB & SMB (“Marion’s Case”) [1992] 175 CLR 218 at [48].

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.”³⁹

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 in affected populations and a resulting inability to establish control groups monitoring risk levels in intact individuals.

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.³⁶

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.³⁷

We regard these as cultural, not functional, requirements; and the stated psychosocial rationales lack evidence.

APEG notes “particular concern regarding sexual function and sensation” following these interventions.³⁷

³⁹ 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

No long-term follow-up takes place in Australia,³⁷ and handover from paediatric to adult services results in poor access to healthcare by adults, and a lack of clinical data on adult 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.*⁴⁰

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

Exemptions in a 2013 Australian government framework against Female Genital Mutilation describe intersex infants as neither female or male, regardless of their actual sex assignment, until they receive surgical reinforcement of those sex assignments. The framework 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”.⁴¹

This process can be described as a monsterring of intersex infants and children. Morgan Holmes identifies this process as foreclosing a “child’s species membership as a human, and subsequent status as a person”; humanity is obtained only through medical intervention.⁴²

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

⁴⁰ 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.

⁴¹ 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>

⁴² Holmes MM. Mind the Gaps: Intersex and (Re-productive) Spaces in Disability Studies and Bioethics. *Journal of Bioethical Inquiry*. 2008;5(2-3):169–81.

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.

The evidence suggests that a human rights consistent framework ... must necessarily operate from a presumption in favour of maintaining the status quo for as long as possible³⁶

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”.⁴³ The government commended controversial and ineffective 2013 ethical guidelines produced in the State of Victoria; the guidelines permit so-called “normalising” interventions for social and psychosocial rationales.

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.⁴

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.

Cases before the federal Family Court in both 2016 and 2017 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.⁴⁴

⁴³ Attorney General’s Department. Australian Government response to the Senate Community Affairs References Committee reports on involuntary or coerced sterilisation. 2015 May.

⁴⁴ Jones M. Children’s Health Rights and Gender Issues. In: Children’s Rights in Health Care. Leiden: Brill; 2017 (forthcoming).

8 The Family Court of Australia

Among other cases, a 1993 case cited by the Chief Justice of the Family Court in her submission to the 2013 Senate inquiry, and two cases adjudicated by the Family Court of Australia in 2016 and 2017, give rise to serious concerns about access to justice, undue restrictions on legal capacity, and legal and governmental complicity in harmful, current clinical practices.

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 Chief Justice cited the case of *Welfare of a Child A* [1993] FamCA 68.⁴⁵ 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.⁴⁶ 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

⁴⁵ Family Court of Australia. *Welfare of a Child A* [1993] FamCA 68; (1993) FLC 92-402 16 Fam Lr 715 Children (30 June 1993). Available from: <http://www.austlii.edu.au/au/cases/cth/FamCA/1993/68.html>

⁴⁶ 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.

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 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 assert that the “appalling situation” is not the adolescent’s identity, which we note is in line with his legal sex, but the early surgical intervention that prevented him from freely exercising autonomy over his own body. The situation presented in the judgment could have been avoided by deferring all surgeries until the child was able to provide informed consent. 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. No assessment of the purpose or inappropriateness of those early “feminising” surgeries for the child in this case was made, yet the impact of the initial surgical intervention (and also later surgeries following Family Court assent) was significant, and will remain lifelong.

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.²⁹

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”.”⁴⁷ That is, the Chief Justice of

⁴⁷ 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:

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 taken by the parents of a child pseudonymously named Carla, with participation as a friend of the court by an anonymous State government department.

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]),² 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”.²

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]).

However, the medical journal referenced in the judgment was consciously misquoted, seemingly to avoid mentioning the word “intersex”, and the actual “Consensus statement on management of intersex disorders” stating a risk of 28% also states that clinicians should “monitor” gonads in children with 17 beta hydroxysteroid dehydrogenase 3 deficiency.⁴⁸

This information is, however, dated and so should not have been cited as evidence. A more recent clinical review published in 2010 reduces risk levels to 17%.⁴⁹ According to clinical literature, the retention and monitoring of gonads should have been unambiguously supported. It is surprising that a 2006 clinical paper would specify monitoring but an Australian team in 2016 would find this difficult.

Gender stereotyping appears to substantively comprise the rationale for sterilisation, mostly on the basis of parental reporting:

a. Her parents were able to describe a clear, consistent development of a female gender identity;

<http://www.aph.gov.au/DocumentStore.ashx?id=75906320-b2bb-43dd-9d0a-3fe58a7d93f9&subId=16140>

⁴⁸ 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.

⁴⁹ 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.

- 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])²*

We find such stereotyping to be disturbing, and Carla is not yet an independent agent. Given the absence of clear medical evidence in support of Carla's sterilisation, her current gender presentation and future gender identity are irrelevant. 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.⁵⁰

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

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

This restriction on legal capacity directly contravenes article 12 of the Convention.¹⁸ 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 is related to a Victorian 2010 ethical framework's focus on marriage prospects as a rationale for medical intervention, of which more will be discussed later.

The child's sterilisation should not have been approved. Further, this 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]).

⁵⁰ Hewitt JK, Warne GL. Management of disorders of sex development. *Pediatric Health*. 2009;3(1):51–65.

Finally, 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.⁵¹

The Australasian Paediatric Endocrine Group recommends such interventions to address psychosocial rationales despite “particular concern” about post-surgical “sexual function and sensation”,³⁷ and evidence favouring those interventions has been criticised by intersex-led organisations and many other institutions, including the Australian Senate³⁶ and the Committee on Bioethics of the Council of Europe.²⁹ Nevertheless, it is evident that such harmful practices take place within medical settings without any requirement for independent oversight, whether from the Family Court or other avenues.

Overall, this 2016 Family Court of Australia case is deeply disturbing, displaying evidence of heteronormativity, sexism and gender stereotyping, a deliberate disregarding of the child’s future ability to consent, and a conscious avoidance of the word “intersex”.

It is not clear that either parents or Court have been exposed to accurate and comprehensive information medical evidence supporting the interventions on the child, and it appears that the family have had no access to independent peer support. This will have long-term repercussions for the family. As stated by the report of the Council of Europe Committee on Bioethics:

Parental consent is inherently problematic as there is no credible evidence that children benefit from improved attachment with parents who want these interventions. Indeed, parental desire for the interventions complicates the eventual transfer of control over to the children for their own gender and sexuality²⁹

Members and the broader constituencies of OII Australia and AISSGA have been greatly troubled by this case. Board members and other individuals have in many cases personally experienced similar interventions, with negative personal and familial consequences.⁵²

⁵¹ An early case note can be found at: Carpenter M. The Family Court case Re: Carla (Medical procedure) [2016] FamCA 7 [Internet]. OII Australia. 2016 [cited 2016 Dec 7]. Available from: <https://oii.org.au/31036/re-carla-family-court/>

⁵² 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-communitys-approach-intersex-people-still-primarily-focused-normalising>

8.3 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.⁵³

A transgender and intersex 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 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]).

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.

However, this case should not have been necessary. 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.

8.4 Commentary

In her 2013 comments to the Senate inquiry on involuntary or coerced sterilisation, the Hon Diana Bryant, 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

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>

⁵³ Family Court of Australia. *Re: Kaitlin [2017] FamCA 83*. Available from:

<http://www.austlii.edu.au/au/cases/cth/FamCA/2017/83.html>

*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.*⁴⁷

OII Australia 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 Chief Justice and other Family Court justices have had ample opportunities to comment on them. 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 is 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 deeply troubling.

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.

Kerridge, Lowe and Stewart state that:

*the therapeutic/non-therapeutic distinction has completely broken down ... The distinction fails to tell us why some treatments need court approval and others do not... The better approach would be to jettison the distinction altogether and to work from an established list of treatments that require approval.*⁵⁴

They also argue that the distinction appears to have been ineffective “in stopping the number of non-approved sterilisations” of children with disabilities.⁵⁴ This is unsurprising when the Family Court has been willing to grant parental authority to consent to sterilisations of children. The authors also state that the Court process is expensive and cumbersome. The Family Court does not provide adequate, appropriate, independent oversight.

Aileen Kennedy 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”.⁵⁵

⁵⁴ Kerridge I, Lowe M, Stewart C. Chapter 22: Children. In: Ethics and law for the health professions. Fourth edition. Annandale, NSW: The Federation Press; 2013. p. 582–604.

⁵⁵ Kennedy A. Fixed at Birth: Medical and Legal Erasures of Intersex Variations. *UNSW Law Journal*. 2016;39(2):813–42.

9 Victoria

An 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. The ethical framework states:

*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.*⁵⁶

However, these issues persist today. Current guidance published in 2013 is based substantively on a 2010 clinical ethical framework 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.⁵⁷ That 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 relationships*⁵⁷

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 excludes same-sex couples, such rationales are also heteronormative, promoting a heterosexual ideal on people born with intersex bodies. This is evident in *Re: Carla (Medical procedure)*.

The 2010 paper was criticised by some (US-based) 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

⁵⁶ 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>

⁵⁷ 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.

*all involved. The challenge now is not articulation of principles; the challenge is creating a process for implementation.*⁵⁸

The 2010 ethical guidance appears to have been rolled out nationally.⁵⁹ Early genital surgeries are known to occur in Victoria. A press report in The Age newspaper on 20 June 2013 included advocate and clinician interviews, stating:

The Royal Children's Hospital Melbourne ... performs 10 to 15 genital reconstruction operations a year often on girls under the age of two

These were described in the press coverage using terms familiar from the 2016 Family Court case of *Re: Carla (Medical procedure)*, such as "... gender assignment or genital enhancement operations"; outcomes were stated by a clinician at the hospital to be "good", with no pressure to change practices.⁶⁰

Despite such claims, the Royal Children's Hospital made no such claims about outcomes to the 2013 Senate inquiry, stating instead that "...we acknowledge that outcomes related to current approaches remain to be established."⁶¹

We do not believe that any clinical claims of good outcomes were substantiated in submissions to the Senate inquiry; indeed, the report recommendations would have been very different, as would the internationally available evidence. The hospital's statement is evidence, however, of the experimental nature of medical interventions.

Nationally, and at State level, data on numbers of surgeries lack transparency. While the Royal Children's Hospital Melbourne has reported to the media that 10-15 "genital reconstruction operations" on young children each year,⁶¹ a national total of 6 "procedures for anomalies of genitalia" in age groups 0-19 years are detailed in statistics on clinical procedures published by the Australian Institute of Health and Welfare for the year 2013-2014. It appears that data are displaced to other, potentially less contentious, procedure codes.⁶²

⁵⁸ 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.

⁵⁹ 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.

⁶⁰ 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>

⁶¹ Royal Children's Hospital Melbourne. Submission of the Royal Children's Hospital Melbourne 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]; Jul 2013 [cited 1 Aug 2013]. Available from: <http://www.aph.gov.au/DocumentStore.ashx?id=84e279b0-e824-4d4a-9aba-080b11077117&subId=16195>

⁶² 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/>

The derivative 2013 State ethical guidelines were cited in a “Rainbow eQuality” guide published in June 2016, by the Victorian government. It includes positive statements on the health of LGBTI populations:

*The Victorian Government values and celebrates diversity... Inclusion is about recognising and valuing diversity, including a diversity of sexualities, gender identities and intersex variations. Inclusive practice is not about changing individual beliefs or personal values but about ensuring that services are delivered in ways that are non-discriminatory and LGBTI inclusive and welcoming.*⁶³

In documentation on people with intersex traits, this new material raises epistemological issues, stating that intersex advocates make claims or beliefs about clinical practices, while failing to acknowledge similar, or the same, concerns described by UN Treaty Bodies and other human rights institutions:

*Intersex advocacy groups believe intersex children should be raised as either male or female, but that surgeries to remove physical ambiguities should not occur until the child can provide informed consent.*⁶⁴

Despite the rhetoric of a celebration of diversity, other materials published by the State demonstrate a continuation of harmful practices in Victoria. The State’s Department of Health and Human Services 2015 Neonatal Handbook for clinicians directly contradicted the 2013 ethical framework and statements on valuing the diversity of LGBTI populations, and it also demonstrated a failure to educate clinical staff and the general public on the existence of bodily diversity.

The 2015 Neonatal Handbook 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.*⁶⁵

The situation should be treated as a medical emergency ...

⁶³ Department of Health and Human Services. Rainbow eQuality [Internet]. 2006 [cited 9 Jun 2016]. Available from: <https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality>

⁶⁴ Department of Health and Human Services. Health of intersex people [Internet]. 2015 Sep 9 [cited 2 Jun 2017]. Available from: <https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/lgbti%20populations/health-of-intersex-people>

⁶⁵ 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-ebook/congenital-abnormalities/ambiguous-genitalia>

*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 past*⁶⁵

This material was removed from the Department's website in April 2017,⁶⁶ in response to previous public disclosure of such material by OII Australia, including a submission to the Committee Against Torture in June 2016.⁶⁷ 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 8 June 2017) 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 correction is now delayed until 6 months of age or later. Opinion currently varies between centres as to surgical management options.*⁶⁸

That is, it is up to multidisciplinary clinical teams to make their own judgments about indications and techniques for surgery. The Department's current (as at 8 June 2017) "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.*⁶⁹

These statements are directly relevant to the situation described in the 1993 Family Court case *Welfare of a Child A*, which also happens to involve a male child described clinically as a

⁶⁶ OII Australia. Gaslighting in Victoria [Internet]. 2017 May 18 [cited 2017 May 18]. Available from <https://oii.org.au/31391/gaslighting-in-victoria/>

⁶⁷ 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/>

⁶⁸ 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-e-handbook/conditions/congenital-adrenal-hyperplasia>

⁶⁹ 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>

“genetic female” with congenital adrenal hyperplasia, and which was adjudicated in Victoria.⁴⁵ The child in *Re: Carla* was described as having a “clitoral recession”.²

Any early vaginoplasty is not necessary, as infants and children have no purpose for a vagina, and any early vaginoplasty will require later repeat surgeries due to scarring.

Medical interventions during puberty dramatically affect individuals’ ability to remain in school, with lifelong impacts. In independent research by a researcher at the University of New England on 272 people born with atypical sex characteristics published in 2016, multiple people highlighted the impact of medical treatment on their education. The research showed that 18% of respondents born with atypical sex characteristics failed to complete secondary school, compared to an Australian average of 2%. The researcher identified issues including the direct impact of medical interventions during puberty, bullying (including due to physical characteristics), developmental delays, and lack of an inclusive curriculum.⁷⁰

The implications of medical “normalisation” are lifelong, with an impact on sensitivity and sexual function, and also possible incorrect sex assignment. Urinary and other issues may also arise.⁷¹

In relation to hypospadias, the Department states (as at 8 June 2017) that:

*To reduce the psychological impact surgical correction is usually performed in infancy between 6-18 months, if possible as a one-stage procedure but more than one surgery may be required.*⁷²

This limited form of disclosure obscures actual risk levels. In clinical literature, for example, Guido Barbagli describes urethral strictures and surgical complications as a “‘natural evolution’ over time of hypospadias repair”,⁷³ with long-term results over more than 20 years necessary to judge success. Despite this, multiple studies suggest that physical and

⁷⁰ Jones T. The needs of students with intersex variations. *Sex Education*. 2016;16(6):602-18.

⁷¹ Carpenter M, Organisation Intersex International Australia. Women with CAH: “good” results justify surgeries; “bad” results have unclear causes [Internet]. Jun 2015 [cited 16 Jun 2015]. Available from: <https://oii.org.au/29178/rch-cah-two-reports/>

⁷² Department of Health & Human Services. Hypospadias in neonates [Internet]. 2015 [cited 10 Jun 2016]. Available from: <https://www2.health.vic.gov.au:443/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-e handbook/congenital-abnormalities/hypospadias>

⁷³ Barbagli G. Failed hypospadias repair [Internet]. 3rd Surgical Workshop of Complex Uro-Genital Reconstructive Surgery; 2010 [cited 27 Nov 2014]; Serbia. Available from: <http://www.failedhypospadias.com/files/Belgrado2.pdf>

psychological issues associated with hypospadias are overstated.^{74,75} Carmack, Notini and Earp report that half of parents authorising hypospadias surgeries in one study expressed regret after authorising early surgeries.⁷⁵

No State-by-State breakdown appears publicly available, but national data on surgical procedures by the Australian Institute of Health and Welfare is currently available for some periods. The data available for the 2013-2014 year showed that 200 procedures on children and youth in age cohorts up to age 19 were carried out for “repair of postoperative urethral fistula”. That is, 200 repeat procedures were conducted to “fix” iatrogenic problems. 125 of these occurred in the 1-4 years age group.⁶²

The distinctions between statements by the same government department in relation to LGBTI populations and in relation to related individual clinical diagnoses are deeply troubling, and suggest a commitment to managing perceptions of government policy, rather than effecting change to ensure accountability and transparency, and to ensure that clinical practices meet human rights norms.

⁷⁴ Fichtner J, Filipas D, Mottrie AM, Voges GE, Hohenfellner R. Analysis of Meatal Location in 500 Men: Wide Variation Questions Need for Meatal Advancement in All Pediatric Anterior Hypospadias Cases. *The Journal of Urology*. 1995;154(2):833–4.

⁷⁵ Carmack A, Notini L, Earp B. Should Surgery for Hypospadias Be Performed Before an Age of Consent? *Journal of Sex Research*. 2015;53(8):1047-58.

10 Australian Capital Territory

In 2014, the government of the Australian Capital Territory (“ACT”) adopted a policy framework establishing third, fourth and fifth sexes, including “intersex”, and with those classifications available for infants and children, at the same time that the same government defended its medical treatment of infants and children with “DSDs” in correspondence with OII Australia.

The Hon. Katy Gallagher, then the ACT Chief and Health Minister, wrote in April 2014 that the creation of a new sex category would address issues around coercive medical interventions on infants and children:

The availability of the third marker for children will also reduce the risk that parents will force their child to conform to a particular gender or subject them to gender assignment surgery or other medical procedure to match the child’s physical characteristics to the chosen sex⁷⁶

However, a clinical framing of intersex variations as “disorders of sex development” is evident in a contradictory but contemporaneous letter from the same Minister, a couple of months prior:

Currently in the ACT, in the event of a birth of a baby with a disorder of sex development (DSD), clinicians follow a standard investigation and management practice that is consistent with a national approach from the Australasian Paediatric Endocrine Group and international consensus statements from key disciplines such as paediatric endocrinology, surgery... it is recognised that surgery of this sort is best performed in centres of excellence. For this reason children with a DSD are normally referred to either Melbourne or Sydney.⁷⁷

When we review the two letters from the Minister, we observe contradictory statements, denial of responsibility for harmful practices in state-funded hospitals, claims of clinical consensus, and a description of national norms. The letters describe two fundamentally different, both un-evidenced, approaches to the same population.

As described by Morgan Carpenter: “The government was not able to create a well-formed policy because it does not possess a coherent understanding of the population affected”, treating persons with “DSDs” as if they are a separate population to persons with intersex traits.³

The data available to us have shown that no parents in the Australian Capital Territory have used a new sex classification to assign an infant. Indeed, our view is that such novel

⁷⁶ Communication by Katy Gallagher, writing as Chief and Health Minister of ACT, to Morgan Carpenter, then president of OII Australia, 15 April 2014.

⁷⁷ Communication by Katy Gallagher, writing as Chief and Health Minister of ACT, to Morgan Carpenter, then president of OII Australia, 21 January 2014.

assignments reinforce and exacerbate surgical interventions due to a parental desire for perceived certainty, and the avoidance of disclosure and stigma. Clinicians in the Territory participate in APEG.

Fundamentally, the approach to birth registrations adopted in the Australian Capital Territory is based on an inappropriate romanticisation of intersex traits; an imagined “other” that can break down oppressive sex and gender binaries.⁷⁸

In practice, intersex people are extremely diverse in our understandings of our bodies, sexes, and genders, and this should not be reduced to a sex or gender classification. Australian research published in 2016 shows that 52% of persons born with atypical sex characteristics were assigned female at birth, and 41% were assigned male at birth. Genders at the time of the research survey included 52% female, 23% male, while 25% of persons have identities other than solely female or male.⁹¹ One size does not fit all.

OII Australia supports the Darlington Statement by Australian and New Zealand intersex advocates, March 2017.⁶ In relation to birth sex assignments, the Statement calls:

*8. Regarding **sex/gender classifications**, sex and gender binaries are upheld by structural violence. Additionally, attempts to classify intersex people as a third sex/gender do not respect our diversity or right to self determination. These can inflict wide-ranging harm regardless of whether an intersex person identifies with binary legal sex assigned at birth or not.*

*Undue emphasis on how to classify intersex people rather than how we are treated is also a form of structural violence. The larger goal is not to seek new classifications but to **end legal classification systems** and the hierarchies that lie behind them. Therefore:*

- a) As with race or religion, sex/gender should not be a legal category on birth certificates or identification documents for anybody.*
- b) While sex/gender classifications remain legally required, sex/gender assignments must be regarded as provisional. Given existing social conditions, we do not support the imposition of a third sex classification when births are initially registered.*
- c) Recognising that any child may grow up to identify with a different sex/gender, and that the decision about the sex of rearing of an intersex child may have been incorrect, sex/gender classifications must be legally correctable through a simple administrative procedure at the request of the individual concerned.*
- d) Individuals able to consent should be able to choose between female (F), male (M), non-binary, alternative gender markers, or multiple options.⁶*

⁷⁸ Ahmed S. Interview with Judith Butler. *Sexualities*. 2016;19(4):482-92

11 New South Wales

Female Genital Mutilation is criminalised, while routine or ritual male circumcision is no longer performed in public hospitals in this State, due in part to human rights concerns:

*Ethical and human rights concerns have been raised regarding routine infant male circumcision. This is because it is recognised that the foreskin has a functional role, the operation is non-therapeutic and that the infant is unable to consent.*⁷⁹

However, individuals born with non-normative sex characteristics are routinely subjects of medical interventions at an age when unable to personally consent, and no human rights concerns are acknowledged. The State fails to publicly disclose most current practices, however, we understand that APEG policy applies.³⁷ This means that individuals are subjected to medical interventions to fulfil social and cultural rationales.

In relation to hypospadias, the NSW government Sydney Children's Hospital Network states:

*Sometimes more than one operation is required to complete the repair. The need for a second operation may not arise for many years.*⁸⁰

As is the case in Victoria, such limited disclosure fails to adequately describe risks and established poor outcomes from such interventions.

A media statements by a co-chair of the DSD Subcommittee of APEG suggests that "No one would do any cosmetic genital surgery purely because of the parents requesting it",⁸¹ however, this careful statement obscures APEG's own rationales for medical intervention, meaning that clinical recommendation, social stigma, cultural rationales, and parental distress remain key rationales for medical interventions.

⁷⁹ Sydney Children's Hospital at Westmead, Sydney Children's Hospital, Randwick, Kaleidoscope Children, Young People and Families. Male infant circumcision [Internet]. 2015 [cited 2017 Jun 4]. Available from:

http://www.schn.health.nsw.gov.au/files/factsheets/male_infant_circumcision-en.pdf

⁸⁰ Sydney Children's Hospital Network. Hypospadias [Internet]. 2014 [cited 2016 Mar 29]. Available from: <https://www.schn.health.nsw.gov.au/files/factsheets/hypospadias-en.pdf>

⁸¹ Gorman G. Born intersex: The people who are biologically neither male nor female. News.com.au [Internet]. 29 Nov 2015 [cited 2015 Nov 29]; Available from: <http://www.news.com.au/lifestyle/real-life/true-stories/born-intersex-the-people-who-are-biologically-neither-male-nor-female/news-story/5bd9ce6debf9c8b4ab7ca919fb04526c>

12 Queensland

As is the case in Victoria, a rhetoric of changed clinical practices has been asserted by the Queensland government in LGBTI policy contexts,⁸² however, recent statements disclose blunter messaging about surgical “normalisation”.⁸³

In 2012, the Department of Communities in Queensland wrote that:

*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.*⁸²

2016 “Clinical Prioritisation Criteria” for paediatric surgery contain the following statements, calling for urgent referral, itself not inappropriate due to adrenal risks associated with congenital adrenal hyperplasia, but including prioritisation of referral to a paediatric surgeon:

*Ambiguous genitalia and neonatal bilateral undescended testes are urgent referrals to service
Penile conditions ... Disorder of sexual development (DSD) – refer to paediatric surgeon or paediatric medicine immediately*⁸⁴

Adrenal risks associated with congenital adrenal hyperplasia need urgent assessment, for what the Committee on Bioethics of the Council of Europe describes as “administration of endocrine treatment to prevent fatal salt-loss in some infants”,²⁹ but this has no relationship to surgical assessment.

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

⁸² Department of Communities, Queensland. Engaging Queenslanders: A guide to working with Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) communities. 2012.

⁸³ Queensland Health. Queensland Sexual Health Strategy [Internet]. 2016 [cited 2017 Jun 4]. Available from: <https://www.health.qld.gov.au/public-health/topics/sexual-health/strategy>

⁸⁴ Queensland Health. Clinical Prioritisation Criteria – Paediatric Surgery. 2016 Aug 16. Available at <https://cpc.health.qld.gov.au/Specialty/14/paediatric-surgery>

*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.*⁸³

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’.

As described by Ron Amundson:

*The disadvantages experienced by people who are assessed as ‘abnormal’ derive not from biology, but from implicit social judgments about the acceptability of certain kinds of biological variation.*⁸⁵

We note that the Family Court cases of *Re: Carla (Medical procedure)* [2016] FamCA 7 and *Re: Kaitlin* [2017] FamCA 83 were both adjudicated by justices in Queensland, and an anonymised State government department was a party to *Re: Carla (Medical procedure)*. The 2016 document was published in advance of press reporting of the case *Re: Carla (Medical procedure)*, in December 2016,⁵² and prior to *Re: Kaitlin*.

A confidential case of an infant born in Queensland in 2014 was presented by OII Australia to the Office of the High Commissioner for Human Rights in 2015. Multiple surgeries were proposed to modify healthy sex characteristics. We would be grateful if the OHCHR could make this case available to the Committee on the same confidential basis.

In summary, medical interventions take place in pursuit of an arbitrary “normality” that is not realised through surgery, without transparent human rights-based standards of care, and without effective, independent, human rights-based oversight. Medical interventions include experimental treatments; treatments deliberately proceeding prior to a child’s ability to consent; and treatments that may be described as “gender affirmation”, but that take place without adequate or appropriate consultation with the affected child.

⁸⁵ Amundson R. Against normal function. *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*. 2000;31(1):33–53.

13 South Australia

In an approach similar to that of the Australian Capital Territory, and without adequate consultation, the government of South Australia introduced new birth registration categories in 2017, adding that it has acted to:

*remove the requirement that the sex of the child be recorded on the Birth Register where the sex of a child is indeterminate*⁸⁶

This was previously unannounced and it was not sought by intersex-led organisations. As with other policy frameworks, it singles out intersex infants for different treatment and a separate legal status, resulting in concerns about disclosure, access to lesser rights,⁸⁷ and exposure to discrimination.

It is not clear what kind of relationship, if any, the new regulation has with existing actual processes, policies and procedures in hospitals in the State. Clinicians in the State participate in APEG, with the same general clinical principles applying across Australia and New Zealand.

The approach of the South Australian government exemplifies a preoccupation with how to categorise or classify intersex people, rather than with how to respond to our pressing health and human rights concerns.

14 Other States and Territories

We have no specific data available in relation to clinical practices or government policies in Northern Territory, Tasmania or Western Australia. In our view, this absence of evidence should not be regarded as evidence of absence of human rights violations. In part, the absence reflects lack of transparency, systemic epistemological issues, and limited resourcing available to intersex-led organisations.

⁸⁶ Communication by the Hon. Jay Weatherill, Premier of South Australia, and colleagues, to Morgan Carpenter, co-executive director of OII Australia, 18 May 2017.

⁸⁷ For example, marriage is only permissible in Australia between two parties, one of which is legally male and one of which is legally female. In school settings, many activities are gendered, including in sport.

15 Testimonies

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

OII Australia member Alex David and AISSGA president/OII Australia 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".⁵³

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."⁵²

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.

The pressure from the doctors and my family was very, very strong to have corrective surgery. It's not something I would have chosen to do if I had not been forced or highly pressured to be assigned a gender I was not born with.⁸⁸

In 2010, member Michael Noble published testimony that describes a situation with parallels to the Family Court case *Re: Kaitlin*:

⁸⁸ 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>

Around the age of 23, an endocrinologist discovered that my body had never produced enough testosterone for me to undergo a full puberty. He therefore suggested I commence testosterone therapy. Initially, I resisted the pressures placed on me to commence therapy. Yet, eventually, I crumbled under the constant onslaught of threats and horror stories of what my future would be like if I didn't undergo therapy, which the doctors claimed would turn me into a 'real man'. It was insinuated, even blatantly stated on occasions, that my life would be worthless; that I would be a freak; that I would never achieve my potential, and that I would never have any self-esteem (apparently the self-esteem I already had was invalid as it existed outside of the predefined paradigm of being a real man). So, eventually, from the age of 28, after about 6 years of constant threats and 'counselling' by my medical specialists, I began testosterone therapy. And I found it to be a horrifying experience. Testosterone therapy generated profound and traumatic changes in me. I lost contact with who I was and thus my sense of self... I just couldn't function as a 'normal' male, and this caused me significant psychological and physical distress. Worst of all, however, was that the therapy turned me into someone I was not...⁸⁹

Access to necessary medical examinations and procedures can, however, also be unnecessarily challenging. In 2012, Morgan Carpenter, a board member of OII Australia, stated in a submission by our organisation:

I was laughed at by staff at a health insurer for the nature of necessary medical examination. The staff member refused to reimburse the cost, as they didn't cover the examination in men. In a busy public office, this made me blush intensely, but I really needed that money back. Everyone there had overheard and I had nothing left to lose. After a stand up row, her supervisor used her discretionary authority to reimburse an equivalent amount.⁹⁰

Independent research published in February 2016 collected data on 272 people born with atypical sex characteristics. It revealed “strong evidence suggesting a pattern of institutionalised shaming and coercive treatment” affecting respondents.⁹¹ A majority of people who received medical interventions relating to an intersex diagnosis reported at

⁸⁹ Noble M. I am me and I am OK [Internet]. OII Australia. 2010 [cited 2017 May 19]. Available from: <https://oii.org.au/18138/opinion-michael-noble/>

Carpenter M, Organisation Intersex International Australia. Submission on the Involuntary or Coerced Sterilisation of People with Disabilities in Australia [Internet]. OII Australia; 2013 Feb [cited 2013 Aug 31]. Available from: <http://oii.org.au/22613/third-submission-senate-inquiry-sterilisation>

⁹⁰ Carpenter M, Organisation Intersex International Australia. Submission on the proposed federal Human Rights and Anti-Discrimination Bill [Internet]. 2012 Dec [cited 2013 Aug 31]. Available from: <http://oii.org.au/21433/submission-human-rights-anti-discrimination/>

⁹¹ Jones T, Hart B, Carpenter M, Ansara G, Leonard W, Lucke J. Intersex: Stories and Statistics from Australia. Cambridge, UK: Open Book Publishers; 2016.

least one negative impact. A large majority of respondents rejected current medical protocols.

60% of survey respondents had received treatments due to their sex characteristics, half at under 18 years of age. The majority experienced at least one negative impact from treatment.

44% of respondents reported counselling, training or pressure from institutional practitioners (such as doctors or psychologists) aimed at instilling gendered behaviour; 43% reported this from parents.

Stigma, shame and interventions had significant mental health consequences: 60% had thought about suicide, 19% had attempted it (the Australian average is less than 3%).

Personal testimonies show a lack of disclosure of the purpose or nature of medical interventions:

“I was given no information about what had happened and was treated very coldly by nursing staff and doctors. It turned out much of my vagina was missing, but I was not made aware of this until later, and not by staff but by mum whom they told instead of me. I was very angry that they told her over me. I had had so much bleeding from the imperforate hymen surgery that made me confused about what they even did, I felt they had dabbled without my permission and am very distrustful of doctors to this day.”

“[I had surgery for hypospadias] to stop the penis being open to the surface [the surgery] left me with little to no control over my penis during sex. [I was given inadequate information about risks and issues with pain and sensation] ... I wish I had been able to meet other people like me first to know what to do ... But they said there were no groups, which I now know is a lie from the internet and this study.”

An intersex woman with Complete Androgen Insensitivity Syndrome states that gonadectomy (sterilization):

“...exists in my memory as some type of clinical rape; 10 student doctors standing around staring up my vagina as the doctor put his fingers in me and spoke about me like I wasn't there. Everyone was complicit in this, my parents, extended family, the doctors, the state as far as I knew, the whole world.”

Persons with XXY sex chromosomes are regarded by medicine as males with Klinefelter syndrome and an extra X chromosome. Testosterone is typically prescribed in adolescence without regard to the individual's gender identity or, indeed, to attempt to “correct” that identity. A 24-year old intersex woman with XXY states:

I was forced on Testosterone at 15yrs. They tried to correct my body and my behaviour. Now I'm embracing it

Recalling the very high rates of early school leaving in the independent Australian study, an intersex woman with MRKH who dropped out of school after genital surgery and genital examinations by groups of medical students said:

"I was a teenager. I felt like a freak. I didn't know this was possible. I felt like I was very alone and that something was really wrong."

Other testimonies related to schooling include:

"I am a fairly ordinary woman in most respects. The difference is I developed testes instead of ovaries. I also take a large shoe size. I had constant messages and pressure to be feminine as a kid and as a young woman from parents and doctors. Really messed me up. I was given the very loosest process information about my treatments, no messages at all on the risks to my life. I nearly died of septicaemia as a teenager, due to my genital surgery, I missed so much school I actually had to drop out entirely. It changed my whole life. Immense emotional impact to this day."

"My school principal, teacher and counsellor made it hard for me to get the time off school I needed and did not understand the need to deal with the situation in the time it took. My classmates either thought I was a freak or did not understand what was going on and saw me as a bludger trying to get out of class (I was bleeding like a stream from my vagina for god's sake, it is not something you want to say is happening or go to school with)."

"My High School PE Teacher was unaware and my diagnosis was fairly new. She didn't realise my physical inability and lack of desire for physical activity stemmed from an inability to do it due to being way behind my peers, physically. She should have clued in from my sheer extreme tiny size that something wasn't quite right. She then proceeded to bully and harass and even accused me of being a drug addict. I duly informed her it was medical treatment... told her it was none of her business and told her the Principal was aware of my new diagnosis, told her what it was. She had accidentally seen some needle bruise marks... so her confusion was partially justified but the attack without further investigation wasn't!"

In addition to high rates of early school leaving, levels of poverty are comparatively high, with earnings significantly below Australian averages. Consequences of harmful medical practices are lifelong:

"Because I am now wheel-chair bound related to the osteoporosis, related to having my testes removed, I see this as an indirect impact of having a variation, or a direct impact from the surgeries. This affects me every day and

it made the work I used to do (which was physical) impossible to continue, and I had to retrain in administrative skills.”

In contrast to stories of human rights violations regarding medical interventions, some study respondents shared positive stories.

A woman with Partial Androgen Insensitivity Syndrome who was able to refuse genital surgery states:

“I laughed when the doctor proposed it. So I am a little different, so he hasn’t seen genitals like mine before... so? I lived over twenty years without feeling broken, why should I be fixed?... Whose genitals don’t look a little bit funny? Genitals are always kind of ‘their own fish’. Nobody looks like the ideal, we’re all a bit hairy, a bit pokey; at least I can enjoy what I have.”

Stories included ones of connectedness to intersex communities and the difference made by education and an increased visibility of intersex people:

“Meeting happy, healthy intersex people online caused a complete and radical shift in my thinking and wellbeing. Seeing that they had come out about being intersex, and that they liked themselves, that some had partners, and that they sometimes even talked about having had and enjoyed various kinds of sex, that they had found all these ways to have children and jobs and lives... BEST. THING. EVER!”

16 Citation

This paper was written by Morgan Carpenter in consultation with the board of OII Australia. A suggested citation is:

Carpenter M, Organisation Intersex International Australia. Shadow Report submission to the Committee on the Rights of Persons with Disabilities on the situation of intersex people in Australia. 2017 June.