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Contribution to the List of Issues Prior to Reporting to the Committee against Torture for Australia

1. Suggested questions for Government of Australia

A pattern of human rights abuses on infants, children and adolescents with intersex traits persists in Australia, including those that Juan E. Méndez, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, has described as "irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, 'in an attempt to fix their sex', leaving them with permanent, irreversible infertility and causing severe mental suffering."[1]

In many cases, these abuses occur despite rhetoric by Australian governments that asserts the equality and dignity of LGBTI (lesbian, gay, bisexual, transgender, intersex) people, and recognition and valuing of intersex variations.[2]

OII Australia therefore suggests to the Committee to ask the Government of Australia to clarify:

- What action is the government taking to implement the recommendations of a 2013 Senate Community Affairs References Committee report on the involuntary or coerced sterilization of intersex people in Australia?
- How will the government ensure the right of infants, children and adolescents to not undergo experimental, unwanted, irreversible cosmetic interventions to "fix" their sex characteristics, or otherwise assign sex, when their sex characteristics do not fit medical norms for females or males?
- What measures will the government undertake to ensure independent, community-run counselling services for all intersex children and their parents, so as to inform them of the consequences of unnecessary and non-urgent surgery and other medical treatment to decide on the sex of the child and the possibility of postponing any decision on such treatment or surgery until the persons concerned can decide by themselves?

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[1] Méndez J. Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A.HRC.22.53. 2013

[2] Carpenter M. The human rights of intersex people: addressing harmful practices and rhetoric of change. Reproductive Health Matters. Jul 2016; forthcoming.

- How will the government guarantee that full, free and informed consent by the individuals concerned is ensured in connection with medical and surgical treatments for intersex persons; how will it ensure that non-urgent, irreversible medical interventions are postponed until a child is sufficiently mature to direct decision-making and give full, free and informed consent?
- 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 “normalize” intersex bodies?
- How will the government provide redress to people who have undergone unwanted sterilisations and other medical interventions to “normalize” their sex characteristics?

2. Contents

3. OII Australia

Organisation Intersex International Australia Limited (“OII Australia”) is a national, volunteer-run, and intersex-led organisation for people with intersex variations. It 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.

4. Intersex

OII Australia refers to intersex 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 sex characteristics (including genitals, gonads and chromosome patterns) that do not fit typical binary notions of male or female bodies.*[3]

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 legal sexes assigned at birth, our 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[4]; 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).

Some common intersex variations are diagnosed prenatally. Intersex differences may be apparent at birth. Some intersex traits become apparent at puberty, or when trying to conceive, or through random chance.

5. Human rights and intersex people

Article 1 of the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment prohibits coercion on discriminatory grounds inflicting pain or suffering, with State consent or acquiescence (article 1).[5]

In 2013, the UN Special Rapporteur on torture made the first UN statement on how children “born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, “in an attempt to fix their sex” … leaving them

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[3] United Nations, Office of the High Commissioner for Human Rights. Free & Equal Campaign Fact Sheet: Intersex [Internet]. 2015 [cited 5 Sep 2015]. Available from: https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf

[4] Olaf Hiort, 2013, *I-03 DSDnet: Formation of an open world-wide network on DSD* at clinician conference, “4th I-DSD Symposium”, June 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

[5] United Nations. Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment [Internet]. 1984 [cited 16 Apr 2016]. Available from: http://www.ohchr.org/Documents/ProfessionalInterest/cat.pdf

with permanent, irreversible infertility and causing severe mental suffering."[1] These practices are documented in Australia and, indeed, remain current policy.

A UN interagency statement on involuntary or forced sterilization followed the Special Rapporteur's report, in 2014,[6] and this was followed by a WHO report on 'Sexual health, human rights and the law' in 2015.[7] The Committee against Torture has since commented on unnecessary and irreversible sex determining surgeries in China,[8] and Hong Kong.[9] Similar statements on harmful practices have also been made by the UN Committee on the Rights of the Child, and the UN Committee on the Rights of Persons with Disabilities.

In 2013, an Australian Senate committee inquiry into involuntary or coerced sterilisation made recommendations to change clinical practices in Australia to align them with international human rights norms; the report has not been implemented. In 2015, the Council of Europe's Human Rights Commissioner recognized a right to *not* undergo sex assignment treatment; while not directly applicable to Australia, we believe that the report has global relevance.[10]

We note that there is no clinical consensus regarding indications, timing, procedure or evaluation of surgical interventions to "normalise" intersex bodies.[11] We also note concern by Kirsten Sandberg (UN Committee on the Rights of the Child) that "parents have no right to consent to" sex assignment or "normalizing" 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."[12]

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[6] WHO, OHCHR, UN Women, UNAIDS, UNDP, UNFPA, et al. Eliminating forced, coercive and otherwise involuntary sterilization, An interagency statement. Geneva: World Health Organization; 2014.

[7] World Health Organization. Sexual health, human rights and the law. Geneva: World Health Organization; 2015.

[8] United Nations, Committee against Torture. Concluding observations on the fifth periodic report of China [Internet]. Geneva: United Nations; 2015 [cited 28 Dec 2015]. Report No.: CAT/C/CHN/CO/5 22477 E. Available from: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fCHN%2fCO%2f5&Lang=en

[9] United Nations, Committee against Torture. Concluding observations on the fifth periodic report of China with respect to the Hong Kong Special Administrative Region [Internet]. Geneva: United Nations; 2015 [cited 28 Dec 2015]. Report No.: CAT/C/CHN-HKG/CO/5 22478 E. Available from: http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fCHN-HKG%2fCO%2f5&Lang=en

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

[11] Mouriquand PDE, Gorduza DB, Gay C-L, Meyer-Bahlburg HFL, Baker L, Baskin LS, et al. Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how? Journal of Pediatric Urology. 2016; in press

[12] Sandberg K. The Rights of LGBTI Children under the Convention on the Rights of the Child. Nordic Journal of Human Rights. 2 October 2015;33(4):337–52.

6. The national policy environment

A 2013 inquiry into the involuntary or coerced sterilisation of people with disabilities, and of intersex people, by the Senate of Australia documented current medical practices.[13] Clinical practices are understood to reflect a submission by the Australasian Paediatric Endocrine Group (APEG) to the Senate inquiry, which stated:

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

Management of high cancer risks and urinary issues should not be controversial. However, 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 the 1992 case known as “Marion’s case”. The ruling affirmed a “necessary” distinction between therapeutic and non-therapeutic treatment, despite lack of clarity about how these are distinguished. Therapeutic treatment, including incidental sterilisation, broadly involves treatment of a malfunction or disease; this can be authorised by guardians as necessary, without court approval.[14]

The arbitrary nature of this distinction is failing infants, children and adolescents born with intersex traits. For example, a submission to the 2013 Senate inquiry by Cools and others illustrates the intertwining of therapeutic and non-therapeutic rationales, and decision making on sterilisation using factors unrelated to physical health risks:

> *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.”*[15]

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[13] 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

[14] Department of Health & Community Services v JWB & SMB ("Marion's Case") [1992] at 48.

[15] 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: Community Affairs References Committee; 2013 [cited 26 Oct 2013]. Available from:

In relation to cancer risks, actual risk levels are poorly understood; 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.*[13]

However, we have seen no evidence that Court oversight has ever been sought for “normalising” surgeries; while such interventions contravene human rights norms established by multiple UN Treaty Bodies, they are regarded as unambiguously therapeutic in Australia due to parental distress and psychosocial stigma, even when they take place on healthy intersex bodies.

Regarding “Reconstructive reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis”:

> *The purpose of these procedures is for functional reasons such as to allow a male individual to urinate while standing, and for psychosocial reasons such as to allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing.*[16]

We regard standing to urinate as a cultural requirement for boys; the stated psychosocial rationales lack evidence.

APEG notes “particular concern regarding sexual function and sensation” following these interventions.[16] A submission to the same inquiry by the Royal Children’s Hospital, Melbourne acknowledged that “outcomes related to current approaches remain to be

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

[16] Australasian Paediatric Endocrine Group, Hewitt J, Warne G, Hofman P, Cotterill A. 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]. Australasian Paediatric Endocrine Group; Jun 2013 [cited 28 Jun 2013] p. 1–8. Available from: http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191

established",[17] but no long term follow-up takes place in Australia,[16] and handover from paediatric to adult services results in poor access to healthcare by adults, and a lack of clinical data on adult outcomes.

The subjects of medical treatments are infants and children, but interventions aim to tackle parental distress. While detailing poor outcomes from feminising surgeries, Thomas asks "would parents be prepared to contemplate raising their daughter with uncorrected virilization?".[18] The concept of correction itself predicates an error to be fixed.

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." [19] Parents and clinicians may make decisions based upon delivery room distress,[28] and social and cultural bias.

Dayner, Lee and Houk detail the perspectives of 21 parents of 17 children with 46,XX congenital adrenal hyperplasia, finding that 100% of parents agreed surgery was "done for more 'natural looking' genitalia", and 95% "would consent to surgery if adult sexual sensation reduced". [20] However, Liao et al report in The BMJ that "parental regret can be high",[21] and parents "may not realise that they are de facto opting for experimental surgery on their children",[21] with no credible non-surgical treatment pathways. Parents are unable to provide valid informed consent to experimental surgeries on their children.

In a clinical paper this year, Mouriquand and others distinguish intersex traits where there is a "gender issue" from those where certainty is presumed. The evidence suggests that there is no intersex trait where "gender issues" can be entirely ruled out, so such a distinction necessarily assumes the acceptability of an arbitrary degree of risk of incorrect sex assignment when proposing irreversible treatments to reinforce a specific sex. In such cases, Mouriquand and others comment:

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[17] 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]. Australasian Paediatric Endocrine Group; Jul 2013 [cited 1 Aug 2013]. Available from: http://www.aph.gov.au/DocumentStore.ashx?id=84e279b0-e824-4d4a-9aba-080b11077117&subId=16195

[18] Thomas DFM. Gender assignment: background and current controversies. BJU International. 2004;93, Supplement 3:47–50.

[19] Greenberg JA. Intersexuality and the Law: Why Sex Matters. New York: New York University Press; 2012.

[20] Dayner JE, Lee PA, Houk CP. Medical Treatment of Intersex: Parental Perspectives. The Journal of Urology. Oct 2004;172(4):1762–5.

[21] Liao L-M, Wood D, Creighton SM. Parental choice on normalising cosmetic genital surgery. BMJ. 28 Sep 2015;h5124.

> *It appears obvious that given the complexity and heterogeneity of presentation there is no consensus regarding the indications, the timing, the procedure, and the evaluation of outcome of DSD surgery… The levels of evidence of the answers given by the experts are low… most decisions being supported by team expertise… There is a general acknowledgement among experts that timing, the choice of the individual, and irreversibility of surgical procedures are sources of concerns.*[11]

The same issues apply, in our view, to cases where future gender identity is more likely to match sex assignment at birth. Nevertheless, it is a matter of very deep concern that such surgeries remain commonplace despite a lack of evidence and consensus, and given established harmful consequences.

In its 2013 report responding to submissions on involuntary or coerced sterilisation, the Senate committee noted similar concerns:

> *there is no medical consensus around the conduct of normalising surgery…*
>
> *Normalising appearance goes hand in hand with the stigmatisation of difference…*
>
> *There is frequent reference to 'psychosocial' reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child's avoidance of harassment or teasing, and the child's body self-image, there is great danger of this being a circular argument that avoids the central issues. Those issues include reducing parental anxiety, and ensuring social awareness and acceptance of diversity such as intersex. Surgery is unlikely to be an appropriate response to these kinds of issues.*[13]

In its response to the Senate inquiry, the federal government stated that “the substantive regulation of medical treatment is a matter for state and territory governments”.[22] The government commended 2013 ethical guidelines produced in the State of Victoria.

No Australian government has implemented recommendations from the 2013 Senate committee report.

7. Victoria

An ethical framework on the management of intersex infants, children and adolescents was published in the State of Victoria in 2013, with limited input from community organisations. The ethical framework states:

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[22] Australia, Attorney General’s Department. Australian Government response to the Senate Community Affairs References Committee reports on involuntary or coerced sterilisation. Attorney General’s Department; May 2015.

> *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.*[23]

In reality, these issues persist today. Further, the framework states that psychosocial risks that can be minimized through medical intervention include:

- *risk that the child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding and associated negative consequences*
- *risk of social or cultural disadvantage to the child, for example, reduced opportunities for marriage or intimate relationships*[23]

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, this risk is heteronormative, promoting a heterosexual ideal on people born with intersex bodies.

Much of the document is derived from a 2010 paper by clinicians at the Royal Children's Hospital, Melbourne.[24] The 2010 paper was criticised by other clinicians at the time, as:

> *responding to the major DSD debate of a decade ago, namely over genital surgeries in infancy. Many have now recognized that the central challenge in DSD care is not centered on the surgeries per se, but rather finding a way to help families (and healthcare professionals) overcome the shame and anxious secrecy that may shape minds and force hands in ways that ultimately harm all involved. The challenge now is not articulation of principles; the challenge is creating a process for implementation.*[25]

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

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[23] 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

[24] 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.

[25] 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.

> *The Victorian Government values and celebrates diversity. It affirms the right to equality, fairness and decency for Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex (LGBTI) Victorians and is committed to removing discrimination from Victorian laws, services and society… 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.*[26]

In documentation on people with intersex traits, the new guide states that intersex advocates make claims about the beliefs of intersex advocacy groups:

> *Most intersex people are not born with atypical genitalia; however this is common for certain intersex variations. In these cases a decision is made about what sex the child should be raised as shortly after birth. 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.*[27]

Several issues arise in relation to these statements:

- The government minimises human rights concerns with medical interventions on children with intersex traits as only a belief by advocacy groups. It fails to acknowledge statements condemning interventions modifying the sex characteristics of intersex infants, children and adolescents due to their human rights implications, by the 2013 Senate inquiry, the UN Special Rapporteur on Torture, the Committee Against Torture and other Treaty Bodies.
- Current clinical documents published in2015 by the same Department of Health and Human Services directly contradict the limited guidance offered, demonstrating a preference for rhetoric on LGBTI issues rather than implementation of reforms to ensure that clinical practices meet human rights norms.
- These statements represent a failure of the government to commit to actual policy change aimed at genuinely valuing intersex diversity, and protecting people with intersex traits from irreversible, involuntary, harnful and discriminatory treatment.

The same Department's current Neonatal Handbook for clinicians directly contracts the 2013 ethical framework and statements on valuing the diversity of LGBTI populations, and also demonstrates a failure to educate clinical staff and the general public on the existence of bodily diversity.

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[26] 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

[27] Department of Health and Human Services. Health of intersex people [Internet]. 2006 [cited 9 Jun 2016]. Available from: https://www2.health.vic.gov.au/about/populations/lgbti-health/rainbow-equality/lgbti%20populations/health-of-intersex-people

The current Neonatal Handbook describes the birth of an intersex infant with ambiguous genitalia as, “rarely anticipated and can be a source of great distress for parents, delivery room and nursery staff.”[28]

> *The situation should be treated as a medical emergency …*
> *Corrective surgery is usually undertaken within the first year of life but timing can be controversial. Very early surgery at under six months of age is less commonly performed than in the past*[28]

Stigma and distress cannot justify discriminatory treatment; such treatment reinforces stigma.

The same Department produces a “Better Health” guide which states, in connection with the intersex trait of congenital adrenal hyperplasia that:

> *Girls with CAH require surgery to restore[sic] the genital appearance to normal…*
> *The clitoral reduction or recession is done is 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…*[30]

Medical interventions during puberty dramatically affect individuals’ ability to remain in school, with lifelong impacts. In independent research by Tiffany Jones 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 impact of medical interventions during puberty, bullying (including due to physical characteristics), and lack of an inclusive curriculum.[29]

The implications of medical “normalisation” are lifelong and extend beyond issues associated with sensitivity, sexual function and possible incorrect sex assignment, for example, in relation to childbirth:

> *Because nearly all girls with CAH have had surgery around the vagina as children, there is scar tissue there. This may not stretch enough to allow*

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[28] Department of Health and Human Services. Ambiguous genitalia in neonates [Internet]. 2015 [cited 18 May 2016]. Available from: https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/congenital-abnormalities/ambiguous-genitalia

[29] Jones T. The needs of students with intersex variations. Sex Education. 11 Mar 2016 [cited 18 Mar 2016];1–17.

> *vaginal delivery, and it is therefore sometimes necessary for a Caesarean operation to be performed to deliver the baby.*[30]

Urinary and other issues may also arise.[31]

In relation to hypospadias:

> *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.*[32]

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";[33] with long-term results over more than 20 years necessary to judge success. Despite this, multiple studies suggest that physical and psychological issues associated with hypospadias are overstated.[34,35] Carmack, Notini and Earp report that half of parents authorising hypospadias surgeries in one study expressed regret after authorising early surgeries.[35]

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, indicating a commitment to managing perceptions of government policy, rather than effecting change to ensure that clinical practices meet human rights norms.

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[30] Department of Health & Human Services. Congenital adrenal hyperplasia (CAH) [Internet]. 2014 [cited 2 Jun 2016]. Available from: https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/congenital-adrenal-hyperplasia-cah

[31] 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/

[32] 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-ehandbook/congenital-abnormalities/hypospadias

[33] 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

[34] 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.

[35] Carmack A, Notini L, Earp B. Should Surgery for Hypospadias Be Performed Before an Age of Consent? Journal of Sex Research. 2015; in press.

8. Australian Capital Territory

In 2014, the government of the Australian Capital Territory 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 as the same government defended its medical treatment of infants and children with “DSDs” in correspondence with OII Australia. 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.[2]

We understand that no parents have used a new sex classification to assign an infant. Indeed, our view is that such novel assignments reinforce surgical interventions due to a parental desire for certainty and the avoidance of stigma. OII Australia supports the statement of the Third International Intersex Forum in Malta, December 2013:

- *To register intersex children as females or males, with the awareness that, like all people, they may grow up to identify with a different sex or gender.*
- *To ensure that sex or gender classifications are amendable through a simple administrative procedure at the request of the individuals concerned. All adults and capable minors should be able to choose between female (F), male (M), non-binary or multiple options. In the future, as with race or religion, sex or gender should not be a category on birth certificates or identification documents for anybody.*[36]

9. Queensland

A confidential case of an infant born in 2014 was presented to the Office of the High Commissioner for Human Rights in 2015. Multiple surgeries were proposed to modify healthy sex characteristics.

10. New South Wales

Female Genital Mutilation is criminalised. Routine or ritual male circumcision is no longer performed in public hospitals 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*

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[36] Various. Public statement by the third international intersex forum [Internet]. Malta; Dec 2013 [cited 26 Oct 2015]. Available from: http://intersexday.org/en/third-international-intersex-forum/ and other sources.

> *functional role, the operation is non-therapeutic and that the infant is unable to consent.*[37]

However, individuals born with atypical sex characteristics are routinely subjects of medical interventions at an age when unable to personally consent. We understand that the APEG policy applies, meaning that individuals are subjected to medical interventions to meet 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.*[38]

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

Public statements by clinicians suggest that "No one would do any cosmetic genital surgery purely because of the parents requesting it",[39] however, this careful statement obscures the fact that APEG rationales for medical intervention apply, meaning that social stigma and parental distress remain key rationales for medical intervention.

11. Case studies

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.[40] A majority of people who received medical interventions relating to an intersex diagnosis reported at least one negative impact. A large majority of respondents rejected current medical protocols.

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

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[37] Sydney Children's Hospital at Westmead, Sydney Children's Hospital, Randwick, Kaleidoscope Children, Young People and Families. Male infant circumcision [Internet]. 2015 [cited 6 Jan 2016]. Available from: http://www.schn.health.nsw.gov.au/files/factsheets/male_infant_circumcision-en.pdf

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

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> *"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 that 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."*

A man raised as a girl said:

> *"[clinical staff] told me I was going to go to sleep because I was sick and the doctor would fix me … they said I had a tummy tear and they would sew it up (they were removing my testicle) … I had felt insane because I dreamed I was a boy for so long and it was actually real and I went through it all for no reason … [I was told] lies and stories that gave me no say in what was happening."*

Experiences of medicalisation include irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, in an attempt to "fix" sex:

> *"At 2 years old they discovered a hole beneath my clitoris which they had considered a willy, and discovered I had female internal organs and could potentially carry a child one day. So they removed anything that conflicted with their idea of a girl. That included my clit, as they thought it made me look like a boy. I was a baby. I was not consulted in any way, I never even knew it happened until I investigated as an adult in my twenties."*

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."*

A transgender intersex woman with Cryptorchidism comments:

> *“I can’t help but feel that I was mutilated and forced to become something I didn’t believe myself to be; male. The scars on my body have faded, but not the ones on my mind”*

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*

A 31-year old trans intersex woman with XXY states:

> *I was initially raised as male despite having lower than normal 5.5 free testosterone level and XXY chromosomes, and my parents tried to masculine me. I had hormone replacement therapy during adolescence and adulthood. However, I could not reliably live as a man the further I progressed into adulthood, and since transitioned to female.*

A lack of clinical education was highlighted by some respondents, including:

> *“Most specialists are not trained in intersex so they don’t know how to give appropriate treatment. Many endocrinologists are good with hormones for other populations but not so experienced with intersex. Most GPs are also not very familiar with it. They are usually understanding and try to do their best but it is frustrating to have to educate them about it all the time.”*

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!"*

A higher percentage of respondents have a disability, compared to the average Australian population, and levels of poverty are relatively high with earnings significantly below Australian averages.

> *"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!”*

12. Citation

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