

Intersex Rights and Freedoms

Morgan Carpenter

Morgan Carpenter is the president of Organisation Intersex International Australia Limited, a national, intersex-led Public Benevolent Institution that engages in systemic advocacy, education and peer/family support. In 2015, Morgan moderated a presentation on intersex to the UN Committee on the Rights of Persons with Disabilities. Morgan is also an advisor to the first international Intersex Human Rights Fund, managed by the Astraea Lesbian Foundation for Justice, and has acted as an expert advisor to a range of governmental and other institutions.

‘Intersex status’ is a new attribute in federal anti-discrimination law that was introduced in 2013, but few institutions have yet responded to this development. Those few have typically focused on the same issues of honorifics, pronouns and toilets that they might address in tackling gender identity discrimination,¹ while media reports frequently suggest that LGBTI people are all gay.² So what does the law say, and what does it mean to address the rights and freedoms of people born with intersex traits?

Intersex people are born with sex characteristics that differ from stereotypical notions of male or female.³ The *Sex Discrimination Act 1984* (Cth) describes the ‘intersex status’ attribute in physical terms, distinguished not only from sexual orientation and gender identity, but also from sex. The definition is broad, ensuring protections for persons perceived to be intersex.

People with intersex variations are a heterogeneous group, with varied kinds of bodies, experiences and identities. Intersex can mean a different number of sex chromosomes; different physical responses to sex hormones; or different developmental hormone balances and anatomies. A German researcher states they comprise ‘at least 40 different entities of which most are genetically determined. An exact diagnosis is lacking in 10 to 80 per cent of the cases’.⁴ Disclosed by a doctor to a parent or an individual, diagnosis remains an inexact science. Around 1.7 per cent of the population may have intersex traits.⁵

As a group, intersex people face a range of health and human rights issues, caught between contrasting visions of who and how we should be. On the one hand, we are seen to have intrinsic ‘disorders of sex development’. Obvious differences result in medical interventions explicitly intended to make intersex bodies conform to social norms for one or other binary sex.⁶ These often take place shortly after diagnosis, whether prenatally, shortly after birth, during childhood and adolescence, or later in life.

On the other hand, many of us face stigma and abuse due to our sex characteristics, whether ‘treated’ or not,⁷ along with ‘misgendering’, treating our gender identities or legal sexes as invalid, and expectations that atypical

sex characteristics make us a third gender or sex.⁸

Addressing the rights and freedoms of people with atypical sex characteristics means addressing the right to be told the truth about our bodies; the right to be informed, and to freedom of association with a community. They include the right to physical integrity, to make our own choices about irreversible treatments to our bodies that are driven by social expectations; the right to freedom from inhuman and degrading treatment,⁹ and the right to determine our own identities.

I. RECOGNITION BEFORE THE LAW

Recognising intersex in law means recognising our shared experience, and our specific health and human rights needs; it does not mean recognising a novel gender or sex classification. Those of us with obvious physical differences may face the same discrimination experienced by many trans people, whether or not we change sex classification.¹⁰ Some of us have non-binary, multiple, or other distinctive gender identities, and these are often informed by our biology, but we don't all share a common identity, least of all a common gender identity. We of course benefit from actions to reduce gender inequality and the stigmatisation of gender non-conformity, but intersex people only share with each other an experience of being born with stigmatised atypical sex characteristics.

Reductive gender-based approaches to intersex have seen us portrayed in the media as the non-binary equivalent of 'trans-exclusionary radical feminists', those who oppose trans women identifying themselves as women.¹¹ The reality is that we oppose this biological determinism: the essentialism that equates intersex characteristics with non-binary gender identity, and the essentialism that disorders our natural human bodily diversity. Both approaches are harmful, and deny agency to intersex individuals to make our own decisions.

Despite the simplistic rationalisations by the ACT Law Reform Advisory Council,¹² which has been rendered from conflating identity and sex, and the deeply flawed changes to the Territory's birth registrations law that followed, our human rights issues cannot be reduced to a novel third checkbox on a form. Assigning infants and children to a third classification is abhorrent when that classification is experimental, not well understood or supported in society, and when it recognises lesser rights in people than the traditional categories. A child may even be confronted with forced disclosure of their stigmatised characteristics at nursery or school.

Not only is a child's assignment to a third classification likely to be incorrect, given our existing range of identities, but the possibility of such assignment increases pressure on vulnerable parents to *avoid* such risks through medical intervention. Having a third classification open only to intersex and/or trans people is more correctly a purification of the binary sexes. It dangerously misses the point. Our key issue is not so much the

existence of binary genders, but what is done medically to make us conform to those norms. Any third classification must be voluntary, opt in by a person who can consent, and open to all; and it must not misassign intersex people as a class.

Indeed, many intersex people already face stigma and failures to recognise **our** birth sex assignment. Sporting history is replete with examples of women being banned from competition after medical testing reveals they have an intersex variation.¹³ The scientific basis for such exclusion has failed to be demonstrated.¹⁴ Worse, medical papers published in 2013 and 2014 disclosed that four elite intersex women athletes were subjected to 'partial clitoridectomies' and sterilisation as part of a coercive process that determined whether or not they could continue competing.¹⁵ Despite being one of the few countries to protect intersex people from discrimination, Australia's legal exemption for competitive sports, contained in the *Sex Discrimination Act*,¹⁶ has an unfortunate global significance.

Several states and territories are currently reviewing sex registration guidelines. Recognising the rights and freedoms of intersex people would mean ending the legal registration of sex, just like societies around the world have ended the registration of race. However, as with ending the registration of race, ending legal sex classification would not mark the end of work to counter discrimination, combat human rights violations and address health disparities. Nor should it; but ending official sex classifications on identity documents would be right.

Some intersex people change sex assignment, and a particular difficulty faced by people in this situation is the imposition of early involuntary or coerced medical intervention to instil or reinforce an inappropriate gender identity.

Birth registration laws have historically been used to ensure that trans people are surgically sterilised before their identity is officially recognised. Local best practice is to end those requirements for trans people. However, world best practice would not only be permitting self-declaration of sex or gender, but prohibiting modifications to sex characteristics for all people, except in cases where there is personal consent or a clear physical necessity.

To date, Australian discussions have perceived this possibility as some kind of furphy, but Malta did precisely this in 2015, along with recognition of rights to gender identity and bodily integrity, and the creation of a 'sex characteristics' attribute in anti-discrimination law.¹⁷ Malta remains the only country in the world that prohibits sex assignment treatments and surgical interventions on minors.

II. MEDICAL TREATMENT

Surgeries and hormonal interventions to 'normalise' intersex bodies currently take place on a routine basis in Australia, such as when girls' clitorises are deemed too



Illustration by Angelina Yurlova

big, or when boys are unable to stand to urinate. The Australian Human Rights Commission reports such rationales as ‘informed by redundant social constructs around gender and biology’,¹⁸ but clinicians argue that standing to pee is a ‘functional’ requirement for boys.¹⁹

Infants assigned as girls may be subjected to ‘feminising genitoplasty’ at an average age of 15 weeks, and follow-up consultations may include sensitivity testing with a cotton bud or vibrator. On non-intersex girls, such surgeries are considered abhorrent,²⁰ prohibited as ‘Female Genital Mutilation’ due, in part, to urinary, sensitivity and other risks.

Most clinical guidelines are confidential, and so are numerical and historical data. Published quantitative data are also lacking, and there is no long term follow-up in Australia,²¹ but scientific and medical papers disclose the central role of surgical interventions.²²

These are justified for social rationales such as marriageability,²³ facilitating parental bonding, and ‘minimizing family concern and distress’.²⁴ In 2013, an Australian Senate Committee Inquiry into involuntary or coerced sterilisation found that there is ‘great danger’ of using such ‘psychosocial’ reasons for medical intervention.²⁵ It suggests these rationales are a ‘circular argument that avoids the central issues[:] ...surgery is unlikely to be an appropriate response to these kinds of issues.’²⁶ Moreover, clinician documents also disclose ‘particular concern’ for post-surgical ‘sexual function and sensation’.²⁷

Clinical papers commonly portray ethical concerns about medical treatment as controversies over surgical timing and the degree of ‘severity’ warranting intervention.²⁸ In reality, the key ethical concerns are matters of rights and freedoms: of informed consent and personal

'Addressing the rights and freedoms of people with atypical sex characteristics means addressing the right to be told the truth about our bodies; the right to be informed, and to freedom of association with a community.'

autonomy.

The 2013 Senate Committee Inquiry found there is 'no medical consensus around the conduct of normalising surgery.'²⁹ Indeed, UK clinicians state 'a schism has developed between clinicians working in paediatric and in adolescent/adult services' due to a lack of evidence for early surgeries and their consequences.³⁰ The same clinicians note an increase in the number of clitoral surgeries on under-14s in the UK in the last decade: 'The widespread practice of childhood genital surgery has meant that there have been very few adults who have not been operated on to enable robust comparative studies to be carried out'.³¹ Doctors favour action, rather than inaction; an 'intervention bias'.³²

At times, sterilisations take place due to elevated cancer risks, however, data about actual risk levels are often sketchy, with no control groups available for comparison. During the course of the Senate inquiry, it was revealed that routine sterilisations of women with Complete Androgen Insensitivity Syndrome no longer take place – risk levels had been overstated – but the date of their cessation is unknown, and there has been no attempt at reparations. Moreover, clinicians have disclosed a range of non-therapeutic rationales for sterilisation such as sex of rearing and expected future gender identity, and these were intertwined with rationales about cancer risk. The Senate was disturbed by the idea that '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'.³³

Clinicians are members of the same society as everyone else, and subject to the same prejudices and fears.³⁴ Research on physicians' attitudes towards 'normal' female external genital appearance is disturbing; it shows that desirability and propensity to suggest surgical reduction are informed not only by specialism (and possible financial benefit), but also by the physicians' gender.³⁵

In June 2015, the Commonwealth government acknowledged the 2013 Senate committee report, but stated that its recommendations are a matter for States and

Territories. In doing so, it commended guidelines that are both non-binding and flawed.³⁶ In contrast, Malta has shown how meaningful action is possible and practicable. Intersex health issues may also be addressed as forms of discrimination and violence,³⁷ and by removing loopholes in prohibitions of Female Genital Mutilation.³⁸

III. A HISTORY OF SILENCE

The intersex movement necessarily focuses much time and energy on ending involuntary and coerced medical treatment, but even if these cease tomorrow, there remain lifelong legacies of trauma, distrust and discrimination.

The philosopher Miranda Fricker describes epistemic or hermeneutical injustice as preventing someone with lived experience from making sense of their own experience. An example is 'the difficulty of making sense of homosexual desire as a legitimate sexual orientation in a cultural-historical context where homosexuality is interpreted as perverse or shameful... forms of understanding available for making sense of homosexuality were crucially uninformed and distorted.'³⁹ Tackling hermeneutical injustice requires a cognitive shift in understanding.

For people with intersex traits, this hermeneutical injustice was at its most profound from the 1950s to the early new millennium, where a culture of secrecy in diagnoses was fostered.⁴⁰ The objective was to 'enable the child have a 'normal' physical and psychosexual development.'⁴¹

That culture of silence gave people with intersex variations no words to describe our sutures, scars and lack of sensation, and no words to understand the commonalities that are shared across the diversity of intersex experiences.

In 2006, an invite-only group led by US clinicians changed clinical language from intersex to 'disorders of sex development',⁴² a move that sociologist Morgan

Holmes states ‘reinstitutionalises clinical power to delineate and silence those marked by the diagnosis; that this silencing is precisely the point of the new terminology’.⁴³ The new language reasserted medical authority in the light of successful intersex advocacy that cast our issues as human rights.⁴⁴ However, it remains deployed in clinical settings, along with specific, rare, and complex diagnostic terms.

Silence does not simply perpetuate a legacy of shame and secrecy, it prevents families and individuals from providing informed consent. Clinical silence and common misunderstandings of intersex as an identity label act as a form of epistemic or hermeneutical injustice. They prevent parents from understanding their child in non-pathological ways, and as a member of a social group protected by the *Sex Discrimination Act*.⁴⁵ Clinical language erects a barrier to alternative treatment paradigms based on self acceptance and respect for personal autonomy.

Separately, a shift in terminology from LGBT to LGBTI over recent years has not yet been matched with an increased understanding of intersex. By focusing only on issues of sexual orientation and gender identity, LGBTI research studies and services frequently fail to address the particularities of intersex experience. Misconceptions frame intersex as something more familiar, viewed with a trans lens, or an LGBT lens. Novel and abstract terminology has also been adopted with scant relevance, and continue to perpetuate hermeneutical injustices.⁴⁶

Intersex issues are thus caught between distinctly different languages and approaches, and legal policy work remains disjointed. It must not remain so. The problematisation of intersex bodies has profound impacts on our education, work and intimate lives; some of this will be documented in a major research study published late in 2015.⁴⁷

Tackling rights and freedoms for people born with intersex traits means recognising our diversity, and the hermeneutical injustices we face. It means tackling medical disordering, interventions, and the silence that surrounds them, through binding regulation and legislation. It means acknowledging a right not to undergo sex affirming treatments.⁴⁸ In the words of the World Health Organization, it includes ‘remedies and redress to the victims of such treatment, including adequate compensation’.⁴⁹

REFERENCES

1. See, eg, Mehnaz Yoosuf, ‘Recognition and Protection for Intersex Persons’ (2015) 52 *Law Institute Journal*; Meredith Griffiths, ‘Universities Could Do More to Include

LGBTI Students, Human Rights Commission Assessment Finds’, *ABC News (online)*, 11 May 2015 <<http://www.abc.net.au/news/2015-05-11/universities-could-do-more-to-include-lgbti-students-new-guide/6461132>>.

2. See, eg, Bellinda Kontominas, ‘Domestic Violence a “Silent Epidemic” in Gay Relationships’, *Sydney Morning Herald (online)*, 30 May 2015 <<http://www.smh.com.au/nsw/domestic-violence-a-silent-epidemic-in-gay-relationships-20150530-1mm4hg>>; Miki Perkins and Rachel Browne, ‘Young Men Remain Alarming Homophobic, Study Finds’, *Sydney Morning Herald (online)*, 31 March 2015 <<http://www.smh.com.au/national/young-men-remain-alarming-homophobic-study-finds-20150330-1mb7ph.html>>.

3. United Nations Office of the High Commissioner for Human Rights, ‘Fact Sheet: Intersex’ (Report, United Nations Office of the High Commissioner for Human Rights) 1.

4. Olaf Hiort, ‘DSDnet: Formation of an open worldwide network on DSD’ (Paper presented at Proceedings of the 4th International Symposium on Disorders of Sex Development, University of Glasgow, 7–9 June 2013).

5. Melanie Blackless et al, ‘How Sexually Dimorphic Are We? Review and Synthesis’ (2000) 12 *American Journal of Human Biology* 151, 159.

6. See Community Affairs References Committee, Parliament of Australia, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) 35.

7. See, eg, Iain Morland, ‘What Can Queer Theory Do for Intersex?’ (2009) 15 *GLQ: A Journal of Lesbian and Gay Studies* 285, 298; Rachel Moss, ‘Married Man Sees His Doctor About Stomach Cramps – Finds Out He’s A Woman With Period Pains’, *Huffington Post UK (online)*, 28 July 2014 <http://www.huffingtonpost.co.uk/2014/07/24/married-man-period-pains-woman_n_5616359.html>.

8. See Julia Baird, ‘Neither Female Nor Male’, *The New York Times (online)*, 6 April 2014 <<http://www.nytimes.com/2014/04/07/opinion/neither-female-nor-male.html>>.

9. Micah Grzywnowicz, ‘Consent Signed with Invisible Ink: Sterilization of Trans* People and Legal Gender Recognition’ (Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture’s 2013 Thematic Report, American University Washington College of Law, 2013) 74.

10. See Morgan Carpenter and Dawn Hough, ‘Employers’ Guide to Intersex Inclusion’ (Guide, Pride in Diversity and Organisation Intersex International Australia Limited, 2014) 18.

11. Baird, above n 8.

12. ACT Law Reform Advisory Council, *Beyond the Binary: Legal Recognition of Sex and Gender Diversity in the ACT*, Report No 2 (2012) 9.

13. Maria José Martínez-Patiño, ‘Personal Account A Woman Tried and Tested’ (2005) 366 (Suppl 1) *The Lancet* S38.

14. *Dutee Chand v Athletics Federation of India (AFI) & The International Association of Athletics Federations (IAAF) (Interim Arbitral Award)* (Court of Arbitration for Sport, CAS 2014/A/3759, 24 July 2015) 34, 155.
15. See, eg, Rebecca M Jordan-Young, Peter H Sönksen and Katrina Karkazis, 'Sex, Health, and Athletes' (2014) 348 *BMJ: British Medical Journal* 20, 20; Patrick Fénelichel et al, 'Molecular Diagnosis of 5 α -Reductase Deficiency in 4 Elite Young Female Athletes Through Hormonal Screening for Hyperandrogenism' (2013) 98 *The Journal of Clinical Endocrinology & Metabolism* E1055, E1057-8.
16. *Sex Discrimination Act 1984* (Cth), s 42.
17. *Gender Identity, Gender Expression and Sex Characteristics Act 2015* (Malta) Act No XI of 2015, 14 April 2015.
18. Australian Human Rights Commission, 'Resilient Individuals: Sexual Orientation, Gender Identity & Intersex Rights' (National Consultation Report, Australian Human Rights Commission, 2015) 57.
19. Australasian Paediatric Endocrine Group, Submission No 88 to Senate Standing Committee on Community Affairs, *Inquiry Into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development*, 27 June 2013, 4.
20. Australian Government Attorney General's Department, 'Review of Australia's Female Genital Mutilation Legal Framework' (Final Report, Attorney General's Department, March 2013) 6.
21. *Ibid* 18-9.
22. Lih-Mei Liao and Margaret Simmonds, 'A Values-Driven and Evidence-Based Health Care Psychology for Diverse Sex Development' (2014) 5 *Psychology & Sexuality* 83.
23. State Government of Victoria Department of Health, 'Decision-Making Principles for the Care of Infants, Children and Adolescents with Intersex Conditions' (Policy Guidelines, Victorian Government, February 2013) 18.
24. S Faisal Ahmed et al, 'Summary of Consensus Statement on Intersex Disorders and Their Management' (2006) 118 *Pediatrics* 753.
25. Community Affairs References Committee, above n 6, 74.
26. *Ibid*.
27. See, eg, Australasian Paediatric Endocrine Group, above n 19; Morgan Carpenter and Organisation Intersex International Australia, Submission No 23 to Senate Committee on Community Affairs, *August Submission to the Senate Inquiry on the Involuntary or Coerced Sterilisation of People with Disabilities*, 29 August 2013, 3.
28. Australasian Paediatric Endocrine Group, above n 19, 5, 9.
29. Community Affairs References Committee, above n 6.
30. Sarah M. Creighton et al, 'Childhood Surgery for Ambiguous Genitalia: Glimpses of Practice Changes or More of the Same?' (2014) 5 *Psychology and Sexuality* 34, 34.
31. *Ibid* 36.
32. A J Foy and E J Filippone, 'The Case for Intervention Bias in the Practice of Medicine' (2013) 86 *Yale Journal of Biology and Medicine* 271, 271-2.
33. Community Affairs References Committee, above n 6, 91-2.
34. See Simon Copland, 'CIA Torture Is Only Part of Medical Science's Dark Modern History', *The Guardian* (online), 22 June 2015 <<http://www.theguardian.com/science/blog/2015/jun/22/cia-torture-is-only-part-of-medical-sciences-dark-modern-history>>.
35. Welmoed Reitsma et al, 'No (Wo)Man Is an Island- The Influence of Physicians' Personal Predisposition to Labia Minora Appearance on Their Clinical Decision Making: A Cross-Sectional Survey' (2011) 8 *The Journal of Sexual Medicine* 2377, 2382.
36. Commonwealth, *Parliamentary Debates, Senate*, 17 June 2015, 3756-770 (Mitch Fifield); see also Morgan Carpenter and Organisation Intersex International Australia, Submission No 23 to Senate Committee on Community Affairs, *Supplementary Submission on the Involuntary or Coerced Sterilisation of People with Disabilities in Australia*, 8 March 2013.
37. World Health Organization, 'Sexual Health, Human Rights and the Law' (Report, World Health Organization, 2015) 40.
38. Morgan Carpenter and Organisation Intersex International Australia, Submission No 23 to Senate Committee on Community Affairs, *Third Submission to the Senate Inquiry on the Involuntary or Coerced Sterilisation of People with Disabilities*, 3 June 2013, 3.
39. Miranda Fricker, 'Forum on Miranda Fricker's Epistemic Injustice: Power and the Ethics of Knowing' (2008) 61 *Theoria* 69, 70.
40. See generally Morgan Holmes, 'Is Growing up in Silence Better Than Growing up Different?' (1997) 2(5) *Chrysalis: The Journal of Transgressive Gender Identities* 1, 7-9.
41. Swiss National Advisory Commission on Biomedical Ethics, 'On the Management of Differences of Sex Development: Ethical Issues Relating to 'Intersexuality'' (Report, Swiss National Advisory Commission on Biomedical Ethics, November 2012) 8.
42. Androgen Insensitivity Syndrome Support Group (AISSG), *DSD Terminology* (29 October 2014) AISSG <<http://www.aissg.org/DEBATES/DSD.HTM>>.
43. Morgan Holmes, 'The Intersex Enchiridion: Naming and Knowledge' (2011) 1 *Somatechnics* 388, 388.
44. Georgiann Davis, "'DSD is a Perfectly Fine Term": Reasserting Medical Authority Through a Shift in Intersex Terminology' (2011) 12 *Advances in Medical Sociology* 178.
45. *Sex Discrimination Act 1984* (Cth).
46. Dean Arcuri, 'Midsumma Says Bye to the Alphabet Soup', *SameSame.com.au* (online), 19 June 2015 <<http://www.samesame.com.au/news/12433/Midsumma-says-bye-to-the-alphabet-soup>>.
47. Tiffany Jones et al, forthcoming.
48. Council of Europe Commissioner for Human Rights, 'Human Rights and Intersex People' (Issue Paper, Council of Europe Commissioner for Human Rights, 12 May 2015) 9.
49. World Health Organisation, above n 37, 27.