

28 June 2022

Alex Greenwich MP
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Dear Alex

Consultation on the Equality Bill

Thank you for inviting contributions in relation to an Equality Bill for New South Wales. We agree that the State is lagging behind developments in other jurisdictions, and we thank you for leading debate about reforms to legislation to ensure that people with innate variations of sex characteristics and LGBT people no longer experience discrimination or harm.

Intersex Human Rights Australia is a national intersex-led charitable company that promotes the human rights and health of people with intersex variations. We engage in resource development, community development, and work to document human rights violations. That work includes action on ending harmful practices in medical settings, prenatal diagnosis and genetic selection, and a range of issues associated with the stigmatisation of bodily diversity.

Intersex people have innate variations of sex characteristics that do not fit medical or social norms for female or male bodies. There are more than 40 different such variations that can be determined prenatally, at birth, during puberty, when trying to conceive a child, or at other times. Examples include androgen insensitivity syndrome, gonadal dysgenesis, micropenis, sex chromosome variations, and congenital adrenal hyperplasia with XX or mosaic sex chromosomes. Because our bodies are perceived as different, we can experience stigmatisation, discrimination and harmful practices, including medical interventions to make our bodies appear or function in ways that are more typically female or male.

Misconceptions frequently associate particular gender identities or sex classifications with innate variations of sex characteristics – for example, an incorrect assumption that intersex people necessarily have non-binary gender identities. People with innate variations of sex characteristics may grow and express the same range of identities as represented in the wider community. Many grow to express an LGBT identity (that is, to be same sex attracted or gender diverse) but equally many grow to identify in other ways (for example, heterosexual and/or cisgender women and men). The development of these identities should lie with the individual as they come to understand themselves and should not be attributed arbitrarily according to medical or social norms or theories. People with innate variations of sex characteristics are at risk of human rights violations irrespective of the

words we use and our agency to express any identity.

The words that individuals use to describe themselves typically respond to what we have been taught by parents and clinicians, and to our experiences of misconceptions. We encourage respect for our diversity as a population, including respect for the diversity of our identities, and for the nomenclature that individuals use.

Since December 2016, Intersex Human Rights Australia has two part-time staff positions funded by foreign philanthropy to engage in systemic advocacy. We have no core funding from Australian governments, and we rely on volunteer labour. While the New South Wales government funds support for LGBT people, it has never funded peer and family support and advocacy for people with innate variations of sex characteristics. Existing LGBTQ and LGBTI services do not meet these needs, and existing intersex-led organisations have no public funding to provide these essential services to children and adults with innate variations of sex characteristics and our families. Resourcing for intersex-led community organisations to provide these services would implement recommendations 2 and 10 of the 2021 report on the health and human rights of people born with variations of sex characteristics by the Australian Human Rights Commission.¹ Despite our best efforts, no such funding is currently envisaged in the NSW Health LGBTI Health Strategy,² and no proposals are under discussion in the State.

Unfortunately, the timing of your consultation coincides with consultation on Australian-first legislative protections for people with innate variations of sex characteristics in medical settings in the ACT. It also coincides with urgent work including grant renewal with our primary foreign philanthropic donor, and work to conclude a project for the Victorian Department of Health developing patient resources. These impose pressures that mean we are unable to provide a detailed and thorough submission.

Nevertheless, we have been pleased to meet with you and your Policy Officer, bringing together interested people with innate variations of sex characteristics who have experience of medical interventions in NSW. We also take this opportunity to outline key areas of concern where we believe action is warranted.

Protecting people with innate variations of sex characteristics in medical settings

The most urgent, long-standing and intractable issue we face is the persistence of human rights abuses in medical settings.

A 2016 clinical audit of cases taken to multidisciplinary team meetings in Sydney and Melbourne found that referrals to such teams was much less frequent in Sydney than Melbourne (24 new referrals in Sydney between August 2012 and May 2016 compared to

¹ Australian Human Rights Commission, *Ensuring Health and Bodily Integrity: Towards a Human Rights Approach for People Born with Variations in Sex Characteristics* (Australian Human Rights Commission, 2021) <<https://humanrights.gov.au/intersex-report-2021>>.

² NSW Health, *NSW LGBTIQ+ Health Strategy 2022-2027* (2022) <<https://www.health.nsw.gov.au/lgbtiq-health/Pages/default.aspx>>.

53 new referrals in Melbourne between January 2014 and May 2016).³ No long-term outcomes can be discerned. Of the genitoplasties mentioned in the audit, two took place at a mean age of 18 months, with 'deferral' of three other genitoplasties. The timeframe for 'deferral' (whether, for example, to age two years, or age 12 or 18) is not disclosed. Genitoplasties that were not the subject of clinical debate as a 'treatment dilemma' are not disclosed.

The authors suggest that such teams 'provide a viable alternative to involvement of the Family Court'.⁴ In our view, this approach has evolved out of the failure of the Family Court to provide an effective independent oversight of clinical decisions, but it represents a failure to ensure independent external oversight, and it promotes group think decision making of only a subset of cases, without adequate consideration of human rights and ethical considerations.

In 2020, two NSW paediatric endocrinologists suggested that 'surgical options' are a valid rationale in determining sex assignment in situations of doubt.⁵ The same clinicians also made a number of other deeply concerning statements. In particular, the authors suggest that 'lack of universal interpretation of 'medically necessary surgery' means that such interventions cannot be regulated, while stating that 'no consensus in relation to the need for, or optimal timing of, many surgical interventions' justifies the use of individual clinician judgement in proposing such interventions.⁶ This exemplifies a self-serving situation where evidence and lack of evidence, and clinical 'consensus' and lack of consensus, each support early surgical interventions; this is an indication that it is clinical values and beliefs that underpin treatment.⁷

Gender stereotypes remain evident in clinical thinking. For example, girls with intersex traits have been subjected to surgeries to 'enhance' the appearance of their genitalia,⁸ while boys are subjected to 'functional' surgery aimed at ensuring 'appropriate' urination; that is,

³ Komal A Vora et al, 'Multidisciplinary Team (MDT) Review of Management Decisions in Disorders/Differences of Sex Development (DSD): Experience of Two Paediatric Tertiary Hospital Networks' (at the Australasian Paediatric Endocrine Group Annual Scientific Meeting – APEG 2016, Alice Springs, NT: Alice Springs Convention Centre, 14 August 2016).

⁴ Ibid.

⁵ Komal A Vora and Shubha Srinivasan, 'A Guide to Differences/Disorders of Sex Development/Intersex in Children and Adolescents' (2020) 49(7) *Australian Journal of General Practice* 417, 418.

⁶ Ibid 420.

⁷ I discuss these issues in Morgan Carpenter, *Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data* (University of Huddersfield, May 2022) <<https://morgancarpenter.com/intersex-dsd-australian-data/>>.

⁸ Andrew Bock, 'It Takes More than Two', *The Age* (online, 20 June 2013) <<http://www.theage.com.au/national/it-takes-more-than-two-20130619-2oj8v.html>>; Morgan Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (2018) 20(2) *Health and Human Rights* 205.

urination while standing.⁹ Such surgeries are associated with impaired sexual function and sensation,¹⁰ and experiences of shame.¹¹

The NSW clinical authors also propose a straw man argument, that ‘Some patient groups advocate a complete moratorium on any genital/gonadal surgery until the individual is able to give informed consent’.¹² This claim was refuted in 2021 by the Australian Human Rights Commission, which stated ‘neither the Commission nor any stakeholders have advocated such a blanket prohibition’.¹³

The ACT government draft bill, published in May 2022,¹⁴ arises out of a commitment made in 2019,¹⁵ and deep engagement with community, clinicians, and human rights, bioethics and legal expertise. We commend this bill as a basis for reform in New South Wales.

The ACT government bill implements demands in the Darlington Statement of intersex community organisations and advocates in our region,¹⁶ and the Yogyakarta Principles plus 10, of which I was pleased to be a co-drafter.¹⁷ Action on this issue implements recommendations 1, 4, 7, 8 and 9 of the 2021 Australian Human Rights Commission report ‘*Ensuring health and bodily integrity: towards a human rights approach for people born with*

⁹ April McLennan, “‘People Just Can’t Comprehend’ What It Means for Robert to Have Been Born Intersex’, *ABC News* (online, 14 March 2021) <<https://www.abc.net.au/news/2021-03-14/push-to-outlaw-gender-assignment-surgery-on-intersex-children/13234680>>; Australasian Paediatric Endocrine Group et al, *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* (Submission, 27 June 2013) <<http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>>; Adrienne Carmack, Lauren Notini and Brian D Earp, ‘Should Surgery for Hypospadias Be Performed Before an Age of Consent?’ (2015) 53(8) *Journal of Sex Research* 1047.

¹⁰ Australasian Paediatric Endocrine Group et al (n 9).

¹¹ Bonnie Hart and Jane Shakespeare-Finch, ‘Intersex Lived Experience: Trauma and Posttraumatic Growth in Narratives’ [2021] *Psychology & Sexuality* 1; Aileen Kennedy, Alice de Jonge and Morgan Carpenter, ‘ACT Releases Australian-First Draft Law to Protect Intersex Children from Irreversible Medical Harm’, *The Conversation* (online, 15 June 2022) <<http://theconversation.com/act-releases-australian-first-draft-law-to-protect-intersex-children-from-irreversible-medical-harm-184566>>.

¹² Vora and Srinivasan (n 5) 420.

¹³ Australian Human Rights Commission (n 1) 131.

¹⁴ Chief Minister, Treasury and Economic Development Directorate, *Protecting the Rights of People with Variations in Sex Characteristics in Medical Settings* (2022); Chief Minister, Treasury and Economic Development Directorate, *Proposed Reforms to Provide Better Care and Support for People with Variations in Sex Characteristics Draft Legislation Consultation* (2022); Chief Minister, Treasury and Economic Development Directorate, Variation in Sex Characteristics (Restricted Medical Treatment) Bill 2022 Consultation Draft 2022. Chief Minister, Treasury and Economic Development Directorate, ‘Protecting the Rights of People with Variations in Sex Characteristics in Medical Settings’.

¹⁵ ACT Government, *Capital of Equality: First Action Plan 2019 & 2020* (2019) <https://www.cmtedd.act.gov.au/__data/assets/pdf_file/0006/1438107/Capital-of-Equality-First-Action-Plan-2019-and-2020.pdf>.

¹⁶ AIS Support Group Australia et al, *Darlington Statement* (March 2017) <<https://darlington.org.au/statement>> (‘*Darlington Statement*’).

¹⁷ Yogyakarta Principles, *The Yogyakarta Principles Plus 10: Additional Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics, to Complement the Yogyakarta Principles* (2017) <<http://www.yogyakartaprinciples.org/principles-en/yp10/>>.

variations in sex characteristics'.¹⁸ It also implements calls for reform by UN Treaty Bodies CEDAW, CRPD, CRC, HRC and CESCR,¹⁹ and addresses calls in 2021 position statements citing IHRA staff by the Australian Medical Association²⁰ and the Public Health Association of Australia.²¹ It is consistent with a 2018 submission to the Australian Human Rights Commission by the Royal Australian and New Zealand College of Psychiatrists.²²

Protections from discrimination and vilification

Current legislation in New South Wales does not protect people with innate variations of sex characteristics from discrimination, and protections from vilification use deprecated terminology ('intersex status') that has fallen behind best practice. Best practice in relation to both discrimination and vilification protections is to provide protections on the ground of 'sex characteristics', as described in the Public Interest Advocacy Centre's 2021 call for reform to the Anti-Discrimination Act.²³ Protections from discrimination on grounds of sex characteristics apply in ACT²⁴ and Victoria,²⁵ with lesser protections in Tasmania,²⁶ and proposals for reform anticipated in Queensland.²⁷

It has sometimes been purported that the ground of 'indeterminate sex' within the attribute of 'transgender status' may have been intended to provide protections from discrimination for people with innate variations of sex characteristics, but this is not the reality and does not appear intended.²⁸ Indeed, enhanced protections in anti-discrimination law relating to 'recognised transgender persons' who have recorded an alteration of sex are irrelevant to the situation of most people with innate variations of sex characteristics, and unavailable as a result. This lack of protection and an erroneous conflation of transgender and intersex

¹⁸ Australian Human Rights Commission (n 1).

¹⁹ Intersex Human Rights Australia, 'UN Treaty Body Statements on Intersex Human Rights in Australia', *Intersex Human Rights Australia* (3 October 2019) <<https://ihra.org.au/35665/australia-crc-crpd-harmful-practices/>>.

²⁰ Australian Medical Association, *Position Statement on LGBTQIA+ Health - 2021* (November 2021) <<https://www.ama.com.au/articles/lgbtqia-health-2021>>.

²¹ Public Health Association of Australia, *The Health of People with Diverse Genders, Sexualities, and Sex Characteristics Policy Position Statement* (2021) <<https://www.phaa.net.au/documents/item/5352>>.

²² Royal Australian and New Zealand College of Psychiatrists, *Re: Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions* (27 September 2018) <<https://www.ranzcp.org/files/resources/submissions/1-president-to-e-santow-hrc-re-intersex-interventi>>.

²³ Public Interest Advocacy Centre, *Leader to Laggard: The Case for Modernising the NSW Anti-Discrimination Act* (August 2021) <<https://piac.asn.au/wp-content/uploads/2021/08/PIAC-Leader-to-Laggard-The-case-for-modernising-the-NSW-Anti-Discrimination-Act.pdf>>.

²⁴ *Justice Legislation Amendment Act 2020* 2020.

²⁵ Victorian Equal Opportunity and Human Rights Commission, 'Public Statement: Sex Characteristics Now a Protected Attribute in the Equal Opportunity Act', *Victorian Equal Opportunity and Human Rights Commission* (26 October 2021) <<https://www.humanrights.vic.gov.au/news/public-statement-sex-characteristics-now-a-protected-attribute-in-the-equal-opportunity-act/>> ('Public Statement').

²⁶ Intersex Human Rights Australia, 'Timeline of Legal, Community and Other Key Events' (9 September 2021) <<https://ihra.org.au/timeline/>>.

²⁷ Queensland Human Rights Commission, *Review of Queensland's Anti-Discrimination Act: Discussion Paper* (2021) <<https://www.qhrc.qld.gov.au/law-reform/have-your-say/discussion-paper>>.

²⁸ AIS Support Group Australia and Anthony Briffa, *Discrimination against People Affected by Intersex Conditions: Submission to NSW Government* (22 January 2003) 18 <<http://www.antidiscrimination.justice.nsw.gov.au/Documents/submission%20about%20intersex%20discrimination%20in%20nsw.pdf>>.

populations have been identified in formal submissions to the NSW government as far back as 2003, so far without reform.²⁹

We recommend that protections extend to the prohibition of genetic discrimination,³⁰ We also recommend that legislation eliminate discriminatory practices in the application of assisted reproductive treatments (and not simply in access to such treatments).³¹ Legislation eliminating discrimination has so far focused on the attributes of people accessing treatment, but it should also attend to the use of assisted reproductive technologies to eliminate fetuses and embryos with particular attributes. As with the elimination of fetuses and embryos on the basis of their sex, the elimination of fetuses and embryos solely on the basis of innate variations of sex characteristics should not be permitted.

For further information on these and related considerations for anti-discrimination law reform we invite you to consider our February 2022 submission to the Queensland Human Rights Commission,³² attached and available at <https://ihra.org.au/39662/submission-qhrc-ada-2022/>

Births, deaths, and marriages reform

At present there remains a tendency in LGBT and legal spaces to believe the fiction that intersex is a sex assignment,³³ or that reform of legislation relating to birth registrations and sex categories can ‘solve’ harmful practices associated with the consequential but distinct processes of medicalisation of children with innate variations of sex characteristics.³⁴ The NSW government has also heard unwise legal claims that propose intersex as a term for a third sex category.³⁵ These are opposed in the Darlington Statement.³⁶

We want to disentangle the experiences of people with innate variations of sex characteristics from proposals to reform sex and gender categories. The word intersex, and

²⁹ AIS Support Group Australia and Briffa (n 28).

³⁰ Jane Tiller et al, ‘Genetic Discrimination by Australian Insurance Companies: A Survey of Consumer Experiences’ (2020) 28(1) *European Journal of Human Genetics* 108 (‘Genetic Discrimination by Australian Insurance Companies’).

³¹ Morgan Carpenter, *Genomics and Genetic Selection* (17 November 2020) <<https://ihra.org.au/eugenics/>> (‘*Genomics and Genetic Selection*’); Edwin P Kirk et al, ‘Gene Selection for the Australian Reproductive Genetic Carrier Screening Project (“Mackenzie’s Mission”)’ [2020] *European Journal of Human Genetics*.

³² Morgan Carpenter and Intersex Human Rights Australia, *Submission on Reform of the Anti-Discrimination Act 1991* (February 2022).

³³ A very recent example can be found in Thorne Harbour Health and Deloitte, *The Cost of Adverse Mental Health Outcomes in the LGBTIQ+ Victorian Adult Population* (March 2022).

³⁴ Morgan Carpenter, ‘The “Normalization” of Intersex Bodies and “Othering” of Intersex Identities in Australia’ (2018) 15(4) *Journal of Bioethical Inquiry* 487; Morgan Carpenter, ‘Intersex Human Rights, Sexual Orientation, Gender Identity, Sex Characteristics and the Yogyakarta Principles plus 10’ (2021) 23(4) *Culture, Health & Sexuality* 516.

³⁵ 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>>.

³⁶ AIS Support Group Australia et al (n 16).

euphemistic terms sometimes associated with intersex traits such as ‘indeterminate sex’, should not be categories for the purposes of birth registration or birth certification.³⁷

We strongly recommend that reform of sex/gender classifications should be consistent with the Australian Bureau of Statistics Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, 2020, which distinguishes innate variations of sex characteristics from sex and gender categories.³⁸ Reforms consistent with this standard are also supported by a 2021 national standard for general practices by the Royal Australian College of General Practitioners.³⁹ IHRA was pleased to contribute to the development of both standards.

For more information on our position in relation to births, deaths, and marriages law reform, we commend our 2022 policy position document, copy attached.

Thank you again for the opportunity to contribute to this important legislative process. We would be pleased to discuss any of these matters with you and your staff and colleagues at your convenience.

Yours faithfully,



Morgan Carpenter
Executive director

³⁷ Carpenter, ‘Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data’ (n 7).

³⁸ Australian Bureau of Statistics, ‘Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, 2020’ (14 January 2021) <<https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release>>; Carpenter, ‘Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data’ (n 7).

³⁹ Royal Australian College of General Practitioners, *RACGP Standards for General Practices (5th Edition) Fact Sheet: Collecting and Recording Information about Patient Sex, Gender, Variations of Sex Characteristics and Sexual Orientation* (2021) <<https://www.racgp.org.au/FSDEDEV/media/documents/Running%20a%20practice/Practice%20standards/5th%20edition/Collecting-and-recording-information-about-patient-sex-gender.pdf>>.