

**Submission
No 18**

EQUALITY LEGISLATION AMENDMENT (LGBTIQA+) BILL 2023

Organisation: Intersex Human Rights Australia (IHRA)

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Submission on the Equality Legislation Amendment (LGBTIQA+)
Bill 2023 (NSW)

Intersex Human Rights Australia (NSW)

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1 Introduction

Thank you for the welcome opportunity to respond to the proposed Bill, which will have enormous positive impact for LGBTIQ+ communities, citizens and residents across NSW. As this submission indicates, Intersex Human Rights Australia broadly supports the proposed amendments, subject to the issues raised below. Specifically, we recommend:

- introducing legislation to eliminate harmful practices on people with innate variations of sex characteristics in medical settings
- drafting changes to ensure consistency in references to our population
- the redrafting of provisions relating to parental consent in the Children and Young Persons (Care and Protection) Act 1988 to ensure that parental rights are not unfettered in ways that have adverse consequences for our population
- replacement of the term intersex in proposed amendments to legislation with the term sex characteristics, to protect all people who may experience stigmatisation or vulnerability due to sex characteristics.

1.1 About this submission

IHRA is a national charitable organisation run by and for people with innate variations of sex characteristics, formerly known as Organisation Intersex International (OII) Australia. We registered as a not-for-profit company in 2010 and became a charity in 2012. Since December 2016 we have been funded by foreign philanthropy to employ two part-time staff to engage in policy development and, more recently, the provision of psychosocial support to individuals and families through the InterLink program.

We promote the health and human rights of people with innate variations of sex characteristics, including rights to bodily autonomy and self-determination. Our goals are to help create a society where intersex bodies are not stigmatised, and where our rights as people are recognised. We build community, evidence, capacity, and provide education and information resources. Our part-time staff and our directors engage in work promoting consistent legislative and regulatory reform, reform to clinical practices, improvements to data collection and research. We also work to grow the intersex movement and the available pool of advocates and peer support workers, and address stigma, misconceptions and discrimination. We deliver the InterLink psychosocial support program for individuals with innate variations of sex characteristics and our families, and this service is funded to mid 2025.

Our work is conducted in line with a 2017 community-designed platform, the *Darlington Statement*, which sets out priorities for the intersex movement in our region.¹ Together with Intersex Peer Support Australia (IPSA, also known as the AIS Support Group Australia) we comprise the Darlington Consortium.

We are willing to meet and discuss our submission if this is thought helpful.

¹ AIS Support Group Australia et al, *Darlington Statement* (March 2017) <<https://darlington.org.au/statement>>. AIS Support Group Australia et al, *Darlington Statement* (March 2017) <<https://darlington.org.au/statement>>.

1.2 Authorship

This submission by IHRA has been written by Dr Aileen Kennedy and Dr Morgan Carpenter with support and contributions from Dr Alice de Jonge.

Dr Kennedy has a PhD in law (UTS). She is the Chair of the board of IHRA and Chancellor's Research Fellow at UTS.

Dr Carpenter has a PhD in bioethics (Sydney). He is Executive Director of IHRA and a Research Affiliate at University of Sydney School of Public Health.

Dr Alice de Jonge has a doctorate in Juridical Science (Melbourne). She is a senior lecturer in law at Monash Business School and an IHRA board member.

3 Examples and experiences of innate variations of sex characteristics

The purpose of this section is to provide sufficient understanding to enable consideration of the impact of laws, policy proposals, and practices affecting people with innate variations of sex characteristics.

Respondents to a large Australian sociological study of people born with atypical sex characteristics in 2015² had more than 35 different variations, including 5- alpha-reductase deficiency, complete and partial androgen insensitivity syndrome (AIS), bladder exstrophy, clitoromegaly, congenital adrenal hyperplasia (CAH), cryptorchidism, De la Chapelle (XX Male) syndrome, epispadias, Fraser syndrome, gonadal dysgenesis, hyperandrogenism, hypospadias, Kallmann syndrome, Klinefelter syndrome/XXY, leydig cell hypoplasia, Mayer-Rokitansky-Küster-Hauser syndrome (MRKH, mullerian agenesis, vaginal agenesis), micropenis, mosaicism involving sex chromosomes, mullerian (duct) aplasia, ovotestes, progestin induced virilisation, Swyer syndrome, Turner's syndrome/X0 (TS), Triple-X syndrome (XXX).

Below we detail the characteristics and experiences of people with several distinct innate variations of sex characteristics due, in some cases, to their higher frequency, and in one case due to the existence of relevant Family Court decisions – including a 2016 decision adjudicated in Brisbane.³

1.3 Androgen insensitivity

Persons with androgen insensitivity syndrome ('AIS') have XY sex chromosomes (typically associated with men), testes (typically intra-abdominal), and a phenotype or physical appearance that may vary. The majority of people with complete AIS appear to be cisgender women and a high proportion are heterosexual.⁴ People with partial AIS grow up to understand themselves in diverse ways, including many women and girls with a largely typical female phenotype, and people who look and understand themselves in different ways.

Diagnosis may take place at any point during infancy or childhood (for example, if testes are mistaken for herniation) or during puberty (due to lack of menstruation). The nature of AIS means that women with complete AIS ('CAIS') will never 'virilise' ('masculinise') if their gonads are retained or if they take testosterone replacement therapy. Women and girls with partial AIS (PAIS) may experience some virilisation if their gonads are retained or if they take testosterone replacement therapy depending on the degree of insensitivity to androgens. Men and non-binary people with partial AIS may seek virilisation where this is possible. Women and other people with 'higher grades' of partial AIS have limited capability for virilisation.

Once diagnosed, people with AIS are frequently subjected to gonadectomies, or sterilisation.

Historically, rates of potential gonadal tumour risk have been overstated, particularly in the case of complete AIS. Current papers suggest a low gonadal tumour risk of 0.8% associated with the gonads of people with complete AIS⁵. Following sterilisation, individuals require hormone replacement to maintain bone health, libido and general health. Recent peer-reviewed clinical journals have

² Tiffany Jones et al, *Intersex: Stories and Statistics from Australia* (Open Book Publishers, 2016) <<https://researchers.mq.edu.au/en/publications/intersex-stories-and-statistics-from-australia>>.

³ *Re Carla* [2016] FamCA 7

⁴ Kerry Warren, 'Hormones, Experimental Surgery & Heartbreak: What It Means To Be Intersex', *Whimn* (online, 8 November 2017) <<http://www.whimn.com.au/talk/think/hormones-experimental-surgery-heartbreak-what-it-means-to-be-intersex/news-story/358596586943a2d7a0f738f56f633239>>.

⁵ J Pleskacova et al, 'Tumor Risk in Disorders of Sex Development' (2010) 4(4–5) *Sexual Development* 259.

established that rates of gonadal tumours in people with partial AIS are also so low that they do not justify early prophylactic sterilisations⁶.

People with AIS report assumptions behind medical intervention that include the idea that women and girls with AIS should not have testes. These include assumptions that women with complete AIS need oestrogen as post-sterilisation hormone replacement, even though their bodies naturally produced testosterone. **People with partial AIS may experience surgeries and other treatments that fail to respect their self-understandings, values and preferences.**

We are aware of clinical claims that prophylactic sterilisations of women with complete AIS no longer take place, including claims that such interventions are 'in the past'. For example, the Australasian Paediatric Endocrine Group stated

*a trend toward consideration of less genital and gonadal surgery in infants assigned female, or delaying surgery. It is important to note that current practice has changed significantly from the past*⁷

However, we are unable to pinpoint any moment in time that divides that past from the present, and we are unaware of any Australian women with AIS aged under 50 who have not been sterilised. It was only very recently, in 2019, that a team of clinicians in the United States published a first management protocol for preservation of gonads in individuals with AIS.⁸ We have no evidence that such protocols are being taken up in New South Wales or the rest of Australia.

In 2019, a clinical team in Brisbane published a review of cases managed by the Paediatric and Adolescent Gynaecology Service where, likely following age of diagnosis, 'In CAIS, bilateral gonadectomies were most often done at infancy'; all individuals with PAIS were also subjected to gonadectomies.⁹ Practices in New South Wales are not documented. In the absence of concrete local information, we take the position that these practices are as plausibly practiced and prevalent in New South Wales as Queensland.

We are aware of cases where people with AIS have been unaware of their diagnosis, and so unable to manage key aspects of their life, including the consequences of sterilisation.¹⁰

Historically, some women with complete AIS were excluded from competitive sport following chromosomal tests. Some women with partial AIS remain excluded. Women in such situations often have no prior knowledge of their variation, and have suffered humiliation, loss of career and, in at least one documented case, home and relationship.¹¹

⁶ Michele A O'Connell et al, 'Establishing a Molecular Genetic Diagnosis in Children with Differences of Sex Development: A Clinical Approach' [2021] *Hormone Research in Paediatrics* 1 ('Establishing a Molecular Genetic Diagnosis in Children with Differences of Sex Development').

⁷ 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.aphe.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>>.

⁸ Erica M Weidler et al, 'A Management Protocol for Gonad Preservation in Patients with Androgen Insensitivity Syndrome' (2019) 32(6) *Journal of Pediatric and Adolescent Gynecology* 605.

⁹ T Adikari et al, 'Presentations and Outcomes of Patients with Disorders of Sexual Development (DSD) in a Tertiary Paediatric and Adolescent Gynaecology (PAG) Service' (at the RANZCOG Annual Scientific Meeting 2019, Melbourne, 2019) <<https://ranzcoasm.com.au/wp-content/uploads/2019/10/243.pdf>>.

¹⁰ For example, see Faye Kirkland, 'Intersex Patients "Routinely Lied to by Doctors"', *BBC News* (online, 22 May 2017) <<http://www.bbc.com/news/health-39979186>>.

¹¹ Maria José Martínez-Patiño, 'Personal Account A Woman Tried and Tested' [2005] *The Lancet* 366.

Chromosomal testing was abandoned as an unjust method of determining sex before the end of the twentieth century¹² before being reintroduced by World Athletics in recent years. That reintroduction of testing affects women with partial AIS and some other variations such as 17-beta hydroxysteroid dehydrogenase 3 deficiency, and 5-alpha reductase deficiency. This testing is contested, and key evidence supporting testing has been amended to remove an unsubstantiated claim of what Jeré Longman summarises as a ‘causal connection between high testosterone levels and enhanced athletic performance among elite female athletes’.¹³

1.4 Congenital adrenal hyperplasia

Children with congenital adrenal hyperplasia (CAH) may necessitate immediate medical attention from birth to manage salt wasting. Salt wasting is potentially fatal and neonatal bloodspot screening is being introduced nationally to identify and treat children at risk.¹⁴

Children with congenital adrenal hyperplasia and XX chromosomes (typically associated with women) may also have genitalia that appears ‘virilised’ or atypical. Atypical genitalia, and higher rates of same sex attraction and gender transition are problematised in persons with CAH and XX sex chromosomes.

A 1990 paper by Heino Mayer-Bahlburg entitled *Will prenatal hormone treatment prevent homosexuality?* highlights ‘an increase in bisexual and homosexual orientation’ in women with CAH attributing this to prenatal androgen exposure.¹⁵ Research to date has, however, found that a diverse range of potential factors including genetics and environmental factors, may be responsible for sexual attraction.¹⁶ According to a 2010 paper by clinicians in New York City:

*Without prenatal therapy, masculinization of external genitalia in females is potentially devastating. It carries the risk of wrong sex assignment at birth, difficult reconstructive surgery, and subsequent long-term effects on quality of life. Gender related behaviors, namely childhood play, peer association, career and leisure time preferences in adolescence and adulthood, maternalism, aggression, and sexual orientation become masculinized [sic] in 46,XX girls and women with 21OHD deficiency.*¹⁷

These characteristics, including behavioural ‘masculinisation’ were described as ‘abnormalities’. The paper went on to state:

¹² Simpson J et al, ‘Gender Verification in the Olympics’ (2000) 284(12) *JAMA* 1568.

¹³ Jeré Longman, ‘Scientists Correct Study That Limited Some Female Runners’, *The New York Times* (online, 18 August 2021) <<https://www.nytimes.com/2021/08/18/sports/olympics/intersex-athletes-olympics.html>>; BMJ Publishing Group Ltd and British Association of Sport and Exercise Medicine, ‘Correction: Serum Androgen Levels and Their Relation to Performance in Track and Field: Mass Spectrometry Results from 2127 Observations in Male and Female Elite Athletes’ (2021) 55(17) *British Journal of Sports Medicine* e7 (‘Correction’).

¹⁴ Department of Health, *Newborn Bloodspot Screening Condition Assessment Summary Congenital Adrenal Hyperplasia (CAH)* (2020) <https://www.health.gov.au/sites/default/files/documents/2020/02/newborn-bloodspot-screening-condition-assessment-summary-congenital-adrenal-hyperplasia_0.pdf>.

¹⁵ HFL Meyer-Bahlburg, ‘Will Prenatal Hormone Treatment Prevent Homosexuality?’ (1990) 1(4) *Journal of Child and Adolescent Psychopharmacology* 279.

¹⁶ Christopher Richards, ‘Do Your Genes Control Who You’re Attracted to?’ in Genetic Support Network of Victoria (ed), *Connections* (Genetic Support Network of Victoria, 2017) 6 <https://www.gsnv.org.au/media/288183/summer_2017-2018_hr_no_bleed.pdf>.

¹⁷ Saroj Nimkarn and Maria I New, ‘Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency’ (2010) 1192(1) *Annals of the New York Academy of Sciences* 5.

*The rates of gender dysphoria and patient-initiated gender change in this population are higher than the rates ... in the general population... Genital sensitivity impairment and difficulties in sexual function in women who underwent genitoplasty early in life have likewise been reported ... We anticipate that prenatal dexamethasone therapy will reduce the well-documented behavioral masculinization and difficulties related to reconstructive surgeries.*¹⁸

At the time of a 2013 Senate inquiry, this prenatal therapy was available in Australia. The Senate sought to end such interventions due to associated cognitive risks to the children concerned.¹⁹ However, their current status in New South Wales and elsewhere Australia is undocumented.

These rationales for treatment have proven controversial.²⁰ Future clinical papers appear to have abandoned disclosure of such rationales – however, the same treatments, including ‘genitoplasties’, persist. This appears to mean that rationales are now simply undisclosed or undocumented.

Despite acknowledgement of **impaired sensation and sexual function, and higher than typical rates of gender assignment change**, at time of writing a resource published by an agency of the Department of Health in Victoria omits consideration of human rights concerns and normalises early elective surgeries, stating:

*Most surgical correction [sic] is now delayed until 6 months of age or later. Opinion currently varies between centres as to surgical management options*²¹ (our emphasis)

The New South Wales government publishes no information on practices in New South Wales hospitals. In the absence of concrete local information, we take the position that these practices are as plausibly practiced and prevalent in New South Wales as Victoria.

In November 2017, an SBS Insight program on intersex heard from Professor Sonia Grover of the Royal Children’s Hospital Melbourne, commenting that surgical practices today are better than they used to be, evading questions about medical necessity and the pre-empting of personal consent.²² Most research, as in Victoria, occurs with clinicians studying the outcomes they are interested in, on their own patients, i.e. subject to confirmation and ascertainment biases. Victorian research has presented information on ‘vibration’ tests on adolescents and adults, and patient views, in an attempt to justify early interventions, while also reporting separately on adverse urinary issues.²³

¹⁸ Ibid.

¹⁹ Senate of Australia Community Affairs References Committee, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index>.

²⁰ Alice Dreger, Ellen K Feder and Anne Tamar-Mattis, ‘Prenatal Dexamethasone for Congenital Adrenal Hyperplasia: An Ethics Canary in the Modern Medical Mine’ (2012) 9(3) *Journal of Bioethical Inquiry* 277 (‘Prenatal Dexamethasone for Congenital Adrenal Hyperplasia’).

²¹ Safer Care Victoria, ‘Congenital Adrenal Hyperplasia (CAH) in Neonates’ (17 February 2021) <<https://www.safercare.vic.gov.au/clinical-guidance/neonatal/congenital-adrenal-hyperplasia-cah-in-neonates>>.

²² *Insight 2017, Ep 31 - Intersex* (Directed by Insight SBS, November 2017) <<https://www.youtube.com/watch?v=tbiSmmCuiYo&list=PLs348akkootwcPaq6GscWFD0LDCzIH4cF&t=0s&index=5>>; Morgan Carpenter, ‘Fixing Bodies and Shaping Narratives: Epistemic Injustice and the Responses of Medicine and Bioethics to Intersex Human Rights Demands’ (2024) 19(1) *Clinical Ethics* 3 (‘Fixing Bodies and Shaping Narratives’).

²³ Morgan Carpenter, ‘From Harmful Practices and Instrumentalisation, towards Legislative Protections and Community-Owned Healthcare Services: The Context and Goals of the Intersex Movement in Australia’ (2024) 13(4) *Social Sciences* 191.

International evidence shows that outcomes are ‘not encouraging’.²⁴ Kalfa and others, for example, have attempted a systematic review but such a review is rendered impossible by a lack of standardised research methods.²⁵ In their 2024 review in the *Journal of Pediatric Urology*, the authors state:

*A large study involving 1040 people from the European multicenter dsd-life study concludes that many people with a range of DSD conditions appear to be dissatisfied with their sex lives, experience a range of sexual problems and are less sexually active than the general population [30]. The results in women with CAH seemed to vary, but in general surgery had a negative effect on sexual function*²⁶

Women with CAH, following surgery in early childhood, were also more likely to experience additional problems with urinary continence and vaginal stenosis (a narrowing of the vagina).

Kalfa and co-authors describe surgical outcomes that are ‘not encouraging’, how nearly 10% of women with CAH have no clitoris due to surgical intervention, and how patient-reported assessments and clinician-reported assessments of outcomes differ:

*Within the group undergoing feminization surgery, attempts are also being made to consider girls with CAH as a separate group. In a recent study reporting the long-term results of a multicenter European registry study in women with CAH, the results cannot be interpreted as encouraging [35]. One hundred and seventy-four 46, XX individuals were included. A gynecological examination was performed in 84 of whom 9.5% had a missing clitoris, 36.7% had a missing clitoral hood, 22.6% had abnormal large labia and 23.8% had small labia. In 30% of the total study population, sex life was described as poor on the basis of patient-reported outcomes, which contrasts with the positive assessment of outcomes by 97% of clinicians and which emphasizes the need to obtain the patients’ perspective...The current analysis of long-term outcomes did not take into account any additional procedures needed later in life after infant surgery. However, we know that up to 50% of patients after pediatric vaginoplasty require additional procedures later in life to allow coitus.*²⁷

In IHRA’s view, these outcomes are unacceptable. Practices (both historic and current) in NSW are not documented, but we can plausibly expect that they are comparable.

Where these interventions occur without personal fully informed consent, the need for such interventions is not indicated or substantiated. Globally, there remains no accepted evidence to support surgical practices. For example, a 2016 clinical update states that:

There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given by the experts are low (B and C), while most are supported by team expertise... Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding

²⁴ Nicolas Kalfa et al, ‘Adult Outcomes of Urinary, Sexual Functions and Fertility after Pediatric Management of Differences in Sex Development: Who Should Be Followed and How?’ [2024] *Journal of Pediatric Urology* S1477513124000524 (‘Adult Outcomes of Urinary, Sexual Functions and Fertility after Pediatric Management of Differences in Sex Development’).

²⁵ Ibid.

²⁶ Ibid.

²⁷ Ibid.

*the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.*²⁸

1.5 17-beta hydroxysteroid dehydrogenase 3 and related traits

Infants with 17-beta hydroxysteroid dehydrogenase 3 (17 β -HSD3) have XY chromosomes and may have genitals that appear at birth to be somewhere between typically female and typically male. In cases where visible genital variation is evident at birth, the currently proposed World Health Organization International Classification of Diseases ICD-11 beta suggests that gender assignment be made based on a doctor's assessment of the technical results of masculinising genitoplasty, and **that genital surgeries must occur early**. Elimination via selective embryo implantation during IVF is also stated as possible:

*If the diagnosis is made at birth, gender assignment must be discussed, **depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed.** Prenatal diagnosis is available for the kindred of affected patients if causal mutations have been characterized*²⁹

The Australasian Paediatric Endocrine Group acknowledges such interventions, even while advising the Senate in 2013 that such early interventions are controversial and known to be associated with 'particular concern' regarding post-surgical sexual function and sensation.³⁰

Additionally, according to a review paper, rates of gender change in persons with 17-betahydroxysteroid dehydrogenase 3 deficiency assigned female at birth are '39–64% of cases'.³¹ This means that children subjected to feminising genitoplasties may not later come to understand themselves as girls or women.

In 2006, a clinical 'consensus statement' described the risk of gonadal tumours associated with 17 β -HSD3 to be 28%, a 'medium' risk, recommending that clinicians 'monitor' gonads.³² A German multidisciplinary team advised Amnesty International in 2017 that, in any case:

'cancer risk even for the high risk groups is not so high. We can monitor with ultrasound and for tumour markers'.³³

However, risk levels have reduced since with the effect that contemporaneous clinical guidance associates gonadectomy with female sex assignment and not gonadal tumour risks, as stated in

²⁸ Peter A Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85(3) *Hormone Research in Paediatrics* 158 ('Global Disorders of Sex Development Update since 2006').

²⁹ Morgan Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (2018) 20(2) *Health and Human Rights* 205; World Health Organization, '46,XY Disorder of Sex Development Due to 17-Beta-Hydroxysteroid Dehydrogenase 3 Deficiency' in *ICD-11 Foundation* (2022) <<https://icd.who.int/dev11/f/en#/http%3a%2f%2fid.who.int%2fid%2fentity%2f887793448>>.

³⁰ Australasian Paediatric Endocrine Group et al (n 7).

³¹ Peggy T Cohen-Kettenis, 'Gender Change in 46,XY Persons with 5 α -Reductase-2 Deficiency and 17 β -Hydroxysteroid Dehydrogenase-3 Deficiency' (2005) 34(4) *Archives of Sexual Behavior* 399.

³² IA Hughes et al, 'Consensus Statement on Management of Intersex Disorders' (2006) 91 *Archives of Disease in Childhood* 554.

³³ Amnesty International, 'First, Do No Harm: Ensuring the Rights of Children Born Intersex.' (May 2017) <<https://www.amnesty.org/en/latest/campaigns/2017/05/intersex-rights/>> ('First, Do No Harm').

material associated with the relevant World Health Organization ICD-11 classification,³⁴ and 2016 clinical “consensus” statements.³⁵

In 2008, in the Family Court case *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226, a judge approved the sterilisation of a young child with 17β-HSD3. This was intended to prevent the child’s body from virilising at puberty. According to a submission by counsel, the alternative to sterilisation included (at [39]) to:

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

That is, sterilisation was not predicated on clinical urgency regarding cancer risk, but instead to surgically reinforce a female gender assignment and pre-empt later determination. Risks of gonadal tumour were stated to be ‘significant’ (at [40]).

In 2016, a Family Court judge adjudicated the case *Re Carla (Medical procedure)* [2016] FamCA 7. An anonymous government department appeared as a friend of the court. The judge concluded that parents could authorise the sterilisation of a pre-school (5-year old) child with 17β-HSD3, surprisingly claiming that ‘it would be virtually impossible to regularly monitor them for the presence of tumours’ (at [20]). This does not accord with the German experience, or material in a 2006 clinical ‘consensus statement’ that calls on clinicians to ‘monitor’ gonads of people with this trait (Hughes et al. 2006). The judge drew upon affidavits from the child’s multidisciplinary team to describe how (at [30]):

It will be less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure

This indicates a lack of urgency related to tumour potential, in addition to a deliberate constraint on the capacity of ‘Carla’. Gender stereotyping appears to form the substantive basis of the decision to sterilise ‘Carla’, including an assumption of a future female gender identity (at [15]):

- a. Her parents were able to describe a clear, consistent development of a female gender identity;*
- b. Her parents supplied photos and other evidence that demonstrated that Carla identifies as a female;*
- c. She spoke in an age appropriate manner, and described a range of interests/toys and colours, all of which were stereotypically female, for example, having pink curtains, a Barbie bedspread and campervan, necklaces, lip gloss and ‘fairy stations’;*
- d. She happily wore a floral skirt and shirt with glittery sandals and Minnie Mouse underwear and had her long blond hair tied in braids; and*
- e. Her parents told Dr S that Carla never tries to stand while urinating, never wants to be called by or referred to in the male pronoun, prefers female toys, clothes and activities over male toys, clothes and activities, all of which are typically seen in natal boys and natal girls who identify as boys.*

The judge also expressed, at [18], an assumption of future heterosexuality: ‘Carla may also require other surgery in the future to enable her vaginal cavity to have adequate capacity for sexual intercourse’. The judge also stated, when the child was 3-years of age (at [2]):

³⁴ Carpenter, ‘Intersex Variations, Human Rights, and the International Classification of Diseases’ (n 29); World Health Organization (n 29).

³⁵ Lee et al (n 28).

Surgery already performed on Carla has enhanced the appearance of her female genitalia.
(our emphasis)

This statement is quite extraordinary. This was a clitorrectomy and labioplasty (at [16]), which may sometimes be termed a 'genitoplasty' or 'vulvoplasty'. Australia, in common with many other countries, maintains a legal prohibition on Female Genital Mutilation (FGM). FGM refers to all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for 'non-medical reasons'.³⁶ In societies where female genital mutilation is a norm, it is recognised to be carried out to, inter alia, enable a woman to fully participate in society, prepare for adulthood, and meet cultural standards for female appearance.

The World Health Organization and other bodies recognize that medicalization, including as a form of harm reduction, does not justify female genital mutilation. Yet, girls with intersex traits are exempt from such protections, including in the Criminal Law of New South Wales, which permits genital surgery if it 'is necessary for the health of the person on whom it is performed and is performed by a medical practitioner' (Crimes Act 1900 (NSW) s45(3)(a)). The gender stereotyping evident in *Re: Carla (Medical procedure)* [2014] FamCA 7 demonstrates a moral hypocrisy in such exemptions. In the absence of concrete local information confirming such practices do not occur in New South Wales, we take the position that these practices are as plausibly practiced in New South Wales as elsewhere in Australia and the world.

The characteristics and health and human rights context for people with 5 alpha reductase deficiency are substantively the same as the context described above for people with 17βHSD3.

1.6 47,XXY/Klinefelter syndrome

People with Klinefelter syndrome are clinically defined as men with an extra X sex chromosome (i.e. XXY sex chromosomes, or 47,XXY). Klinefelter syndrome is associated with small testes, hypogonadism (low sex hormone levels, in this case low levels of testosterone), and also may be associated with cognitive issues such as ADHD, and a range of other health risks.³⁷ As with other innate variations of sex characteristics, the innate physical characteristics of people with XXY are socially stigmatised. Men with Klinefelter syndrome have poorer socioeconomic outcomes;³⁸ this 2015 clinical review states that 90% of people with Klinefelter syndrome are diagnosed after age 15, and only a quarter of individuals expected to have this variation are ever diagnosed.

It is possible that persons with XXY who are not diagnosed may potentially escape some stigma associated with the variation; alternatively, they may either suffer stigma in silence, or clinical signs may be skewed towards those evident in people more likely to be diagnosed.

Not all people with XXY sex chromosomes are male³⁹ but, due to the current medical paradigm that assumes all people with XXY chromosomes are men, women with XXY and people who understand themselves in other ways face additional challenges in accessing appropriate medical care, with their health and social experiences needs largely unreported.

³⁶ World Health Organization et al (eds), *Eliminating Female Genital Mutilation: An Interagency Statement* (World Health Organization, 2008) (*'Eliminating Female Genital Mutilation'*).

³⁷ Anne Skakkebaek, Mikkel Wallentin and Claus H Gravholt, 'Neuropsychology and Socioeconomic Aspects of Klinefelter Syndrome: New Developments' (2015) 22(3) *Current Opinion in Endocrinology & Diabetes and Obesity* 209 ('Neuropsychology and Socioeconomic Aspects of Klinefelter Syndrome').

³⁸ Ibid.

³⁹ S Röttger et al, 'An SRY-Negative 47,XXY Mother and Daughter' (2000) 91 *Cytogenetics and Cell Genetics* 204.

In 2003, reports emerged, originally in the Western Australian newspaper, that Alex MacFarlane, a person with XXY sex chromosomes living in Perth Hills who identified as 'androgynous', received the first 'X' passport.⁴⁰ Alex had received a birth certificate from Victoria stating 'indeterminate – also known as intersex'. Julie Butler, writing for Western Australian, stated:

*Not all 47XXY people identify as androgynous. Some perceive themselves as male or female, and many, like Alex, were surgically altered at birth to appear male or female.*⁴¹

A legal conflation of intersex with a third category of sex (and with 'indeterminate sex') evident in the birth certification is unfortunate in that it fails to acknowledge the diversity of the population of people with intersex variations. It should never be inferred from this development that all people with XXY, nor all people with innate variations of sex characteristics, wish to be marked as neither female nor male.

1.7 46,X0/Turner syndrome

Women with Turner syndrome are often diagnosed at puberty, when menstruation fails to occur. In such cases, a preliminary diagnosis based on physical characteristics (such as short stature, webbing of the neck and/or cubitus valgus) will typically be confirmed through diagnostic genetic testing. Diagnosis may occur in utero when genetic testing is undertaken to screen for preferred sex and/or unwanted genetic conditions such as Down syndrome.

Turner syndrome is associated in the literature with significantly increased risk of heart disorders, such as aortic dissection, and has been associated with evidence of reduced life expectancy.⁴² Early literature finding significantly increased risks of gonadal cancer have been challenged, and it is now more common for surgical removal to be confined to cases of mosaic Turner women with streak ovaries. Lifetime estrogen therapy is commonly prescribed for Turner women. Turner syndrome women can expect early hearing loss and may suffer the psycho-social side-effects associated with hearing loss.

1.8 Experiences of discrimination

People with innate variations of sex characteristics need protection from discrimination. Intersex people suffer many distinctive forms of discrimination and violence due to our sex characteristics. The Office of the High Commissioner for Human Rights states:

Intersex people are subjected to human rights violations because of their physical characteristics. Intersex children and adults are often stigmatized and subjected to multiple human rights violations, including violations of their rights to be free from torture and ill-treatment, to health and physical integrity, and to equality and nondiscrimination.

Human rights violations include forced and coercive medical interventions; infanticide; restrictions on the exercise of legal capacity and in access to remedies and justice; discrimination in access to education, sport, employment and services. The root causes of

⁴⁰ Julie Butler, 'X Marks the Spot for Intersex Alex', *The West Australian* (Perth, Western Australia, 11 January 2003).

⁴¹ Ibid.

⁴² WH Price et al, 'Mortality Ratios, Life Expectancy, and Causes of Death in Patients with Turner's Syndrome' (1986) 40(2) *Journal of Epidemiology and Community Health* 97.

*human rights violations against intersex people include harmful stereotypes, stigma, taboos, and pathologization (i.e. treating intersex persons as necessarily ill or disordered)*⁴³

These issues are evident in Australia. A 2015 Australian survey of 272 people born with atypical sex characteristics found many individual and systemic examples of discrimination:

- *The researcher found ‘strong evidence suggesting a pattern of institutionalised shaming and coercive treatment’*⁴⁴
- *60% had thought about suicide, while 19% had attempted it.*
- *41% of the survey population earned less than \$20,000 per year, and 63% earned under \$41,000 per year*⁴⁵
- *19% of people born with atypical sex characteristics failed to complete secondary school, due to reasons including the impact of medical interventions during puberty, stigmatisation and bullying on grounds of sex characteristics, and unaddressed issues associated with developmental delays*⁴⁶

The report of UN Office of the High Commissioner for Human Rights notes that:

*Some may feel forced into legal sex and gender categories that they do not identify with, including binary (male or female) and third or non-binary categories*⁴⁷

This lies behind our rejection in the Darlington Statement of associations between intersex variations and exclusion from, or inclusion in, any category of sex as a population.⁴⁸ We support choice at an individual level where this does not impact the rights of others to not be forced into particular legal or social categories. Discrimination is also intersectional. For example, the report also states that:

*Potential future LGBT identities in intersex children are frequently ignored by clinicians or presented as adverse outcomes, and intersex people who are lesbian, gay, bisexual or transgender may face additional burdens of discrimination*⁴⁹

The same is true in relation to experiences of disability, racialisation, and other forms of marginalisation. Instances of discrimination in workplaces and schools reported to us include:

- *Non-renewal of employment contracts due to perceptions of physical traits*
- *Lack of access to reasonable accommodations*
- *Attempts to view genitalia in toilet and other sanitary facilities*
- *Higher life insurance costs due to genetic test results*

⁴³ Office of the High Commissioner for Human Rights, *Background Note on Human Rights Violations against Intersex People* (October 2019) <<https://www.ohchr.org/en/documents/tools-and-resources/background-note-human-rights-violations-against-intersex-people>>.

⁴⁴ Jones et al (n 2).

⁴⁵ Ibid.

⁴⁶ Intersex Human Rights Australia, ‘Demographics’, *Intersex Human Rights Australia* (28 July 2016) <<https://ihra.org.au/demographics/>>; Morgan Carpenter and Agli Zavros-Orr, ‘Education’, *Intersex Human Rights Australia* (7 March 2019) <<https://ihra.org.au/education/>>.

⁴⁷ Office of the High Commissioner for Human Rights (n 43).

⁴⁸ AIS Support Group Australia et al (n 1).

⁴⁹ Office of the High Commissioner for Human Rights (n 43).

In addition, we see issues in workplaces that can, on some occasions, lead to discrimination, such as disrespect for sex registration at birth, and systemic misrepresentation of intersex populations on intake forms and in other data collection.

A 2015 Australian sociological convenience sample of 272 people born with atypical sex characteristics found that individuals whose variations are more physically evident to strangers are more likely to bear the brunt of social discrimination.⁵⁰ Such physical evidence of an intersex variation cannot be assumed to correlate with gender expression or particular gender identities, as they relate to physical characteristics. Where a variation is not evident, an individual may avoid disclosure, or medicalise their intersex trait, to prevent risks of discrimination.

2 Prohibiting harmful practices

Fundamentally, an absence of detailed, concrete data on practices in NSW should not be used to justify an absence of action to address human rights abuses and ethical issues with medical practices. Evidence from comparable Australian and European jurisdictions provides sufficient evidence to act. Recommendations for action by the Senate Community Affairs References Committee, the 2017 intersex community consensus statement (the Darlington Statement),⁵¹ UN Treaty Bodies, and the Australian Human Rights Commission set out a model for reform. As we show below, the ACT has already legislated to eliminate harmful practices on people with innate variations of sex characteristics in medical settings, and the Victorian government expects to introduce legislation into its State Parliament during 2024.

In 2021, the Australian Human Rights Commission (AHRC) made 12 recommendations in a report, *'Ensuring health and bodily integrity'*, aimed at ensuring a human rights-based approach to decision-making on medical interventions. The report builds on recommendations of an earlier Senate committee inquiry on the *'Involuntary or coerced sterilisation of intersex people'*.⁵² It also builds on the following demands in the Darlington Statement:

*7. We call for the immediate **prohibition as a criminal act** of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent. We call for freely-given and fully informed consent by individuals, with individuals and families having mandatory independent access to funded counselling and peer support.*

*22. We call for the provision of alternative, independent, effective **human rights-based oversight mechanism(s)** to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations. The pros and cons for and against medical treatment must be properly ventilated and considered, including the **lifetime health, legal, ethical, sexual and human rights implications**.⁵³*

Some early surgical interventions are necessary for physical health and well-being, or permissible with personal informed consent, but others are justified through appeals to gender stereotypes and

⁵⁰ Jones et al (n 2).

⁵¹ AIS Support Group Australia et al (n 1).

⁵² Senate of Australia Community Affairs References Committee (n 19).

⁵³ AIS Support Group Australia et al (n 1).

medical eminence, and overly loose conceptions of medical necessity and therapeutic treatment that permit these as rationales for treatment and consented to by parents or carers.⁵⁴

Doctors specialising in aspects of physical health have argued that psychosocial factors and mental health are appropriate reasons for early surgical intervention, but professional bodies of psychiatrists and psychologists have rejected these rationales.⁵⁵

Additionally, the AHRC report found it necessary to refute a persistent straw man argument, that some advocates want ‘a complete moratorium on all genital/gonadal surgery until the individual is able to give informed consent’.⁵⁶ Citing a submission by the Australasian Paediatric Endocrine Group, the AHRC commented:

Some stakeholders seemed to base their opposition to any legal sanctions on the premise that all medical interventions modifying sex characteristics would be prohibited, in all circumstances.⁶⁷⁵ However, neither the Commission nor any stakeholders have advocated such a blanket prohibition.⁵⁷

The 2021 AHRC and 2013 Senate committee reports provide a firm basis for legislative reform, and associated oversight, treatment standards, and resourcing of peer and family support and advocacy. The AHRC state that:

There is real risk that, without changes to oversight mechanisms, interventions will continue to be made that are not medically necessary and which could have been deferred under a precautionary approach. Current practice has included interventions that are based on psychosocial rationales, such as gender-conforming treatments. [...] current international and Australian clinical guidance allows clinicians to take psychosocial factors, such as cultural or social pressure, into account as relevant when considering whether an intervention should be proposed.⁵⁸

Morgan Carpenter identifies that, “Engaging with clinical, community, human rights and legal stakeholders, the AHRC identified five human rights principles for medical decision-making in relation to” people with innate variations of sex characteristics:

- ‘Bodily integrity principle’, reflecting the right of all people to autonomy and bodily integrity.

⁵⁴ 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>> (*Ensuring Health and Bodily Integrity*).

⁵⁵ Ibid.

⁵⁶ Mike O’Connor, ‘The Treatment of Intersex and the Problem of Delay: The Australian Senate Inquiry into Intersex Surgery and Conflicting Human Rights for Children’ (2016) 23(3) *Journal of Law and Medicine* 531; 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; Komal A Vora et al, ‘Role of Cross-campus Multidisciplinary Team Meetings in Decision-making for Children and Adolescents with Differences of Sex Development/Intersex’ (2021) 57 *Journal of Paediatrics and Child Health* 1402; ‘ACT Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022’ Letter from Royal Australasian College of Surgeons Health Policy and Advocacy Committee, 17 July 2022 <<https://www.surgeons.org/News/Advocacy/ACT--Variations-in-Sex-Characteristics-Restricted-Medical-Treatment-Bill-2022>>; Carpenter, ‘Fixing Bodies and Shaping Narratives’ (n 22).

⁵⁷ Australian Human Rights Commission (n 54).

⁵⁸ Ibid.

- ‘Children’s agency principle’, including the right to express views regarding treatment, and support to make decisions.
- ‘Precautionary principle’, including deferral of treatment where safe to do so, until children can make their own decisions.
- ‘Medical necessity principle’, understanding that some treatments may be urgent to avoid serious harm.
- ‘Independent oversight principle’, recognising the serious consequences arising from wrong decisions.⁵⁹

The AHRC recommendations are in line with recommendation to Australia by UN Treaty Bodies. UN Treaty Body recommendations to Australia by the Human Rights Committee,⁶⁰ Committee on the Rights of the Child,⁶¹ the Committee on the Elimination of Discrimination against Women,⁶² and the Committee on the Rights of Persons with Disabilities⁶³ leave no doubt that involuntary and unnecessary medical treatments on people with innate variations of sex characteristics are discriminatory, fail to protect the integrity of the person, and are ‘harmful practices’ that must be prohibited. For example, CEDAW stated to Australia in 2018:

The Committee urges that the State party to [...] Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary surgical or other medical procedures on intersex children before they reach the legal age of consent, implement the recommendations made by the Senate in 2013 on the basis of its inquiry into the involuntary or coerced sterilization of intersex persons, provide adequate counselling and support for the families of intersex children and provide redress to intersex persons having undergone such medical procedures⁶⁴

The ACT government has enacted reforms to protect the human rights of people with innate variations of sex characteristics in medical settings.⁶⁵ In line with recommendations by the AHRC, it has provided for criminal penalties where contested medical interventions take place without independent oversight.⁶⁶ Independent oversight has been implemented in a new Restricted Medical Treatment Assessment Board, chaired by former National Children’s Commissioner Megan Mitchell

⁵⁹ Morgan Carpenter, ‘Protecting Intersex People from Harmful Practices in Medical Settings: A New Benchmark in the Australian Capital Territory’ (2023) 29(2) *Australian Journal of Human Rights* 409 (‘Protecting Intersex People from Harmful Practices in Medical Settings’).

⁶⁰ Human Rights Committee, *Concluding Observations on the Sixth Periodic Report of Australia* (No CCPR/C/AUS/CO/6, 1 December 2017).

⁶¹ Committee on the Rights of the Child, *Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Australia* (No CRC/C/AUS/CO/5-6, 1 November 2019).

⁶² Committee on the Elimination of Discrimination against Women, *Concluding Observations on the Eighth Periodic Report of Australia* (No CEDAW/C/AUS/CO/8, 25 July 2018).

⁶³ Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Combined Second and Third Reports of Australia* (No CRPD/C/AUS/CO/2-3, 23 September 2019).

⁶⁴ Committee on the Elimination of Discrimination against Women (n 62).

⁶⁵ Chief Minister, Treasury and Economic Development Directorate, ‘Protecting the Rights of People with Variations in Sex Characteristics in Medical Settings’ (4 April 2023)

<<https://www.cmtedd.act.gov.au/policystrategic/the-office-of-lgbtqi-affairs/variations-in-sex-characteristics-bill>>; ACT Health, ‘Protecting the Rights of People with Variations in Sex Characteristics’ (6 March 2024) <<https://www.health.act.gov.au/services-and-programs/lgbtiq/protecting-rights-people-variations-sex-characteristics>>.

⁶⁶ Carpenter, ‘Protecting Intersex People from Harmful Practices in Medical Settings’ (n 59).

AM.⁶⁷ The ACT government has also established a hospital based paediatric psychosocial support service for people with innate variations of sex characteristics and our families.

The Victorian government has also made commitments to reform,⁶⁸ and expectations are that a bill to introduce an intersex protection scheme will be introduced into the Victorian Parliament during 2024.⁶⁹

The former New South Wales government made a commitment in the 2022 NSW LGBTIQ+ Health Strategy 2022-2027 to benchmark against and collaborate with other jurisdictions. Strategy 3.2 states:

Health and human rights Work with other jurisdictions to promote and embed improved measures to meet the health and wellbeing needs of intersex people⁷⁰

Ahead of the 2023 State election, the now Minister of Health, the Hon. Ryan Park made the following commitment in response to our call to enact “legislation to protect the human rights of people with innate variations of sex characteristics in medical settings, including the provision of effective rights-based oversight”:

Labor will work with intersex organisations and other stakeholders to review current practices.

A Minns Labor Government will ban LGBTIQ+ conversion and suppression practices in New South Wales. Labor will work with survivors and all other stakeholders to develop the legislation that works in NSW. We will do this through a joint working group of NSW Health and the NSW Department of Justice to draft the laws.⁷¹

While this commitment refers to “LGBTIQ+” (containing an “I” for intersex), action to eliminate harmful practices on people with innate variations of sex characteristics was omitted from legislation prohibiting conversion practices that the NSW government brought to Parliament this year.

IHRA was commended by the ACT’s Chief Minister in the first and final readings of the legislation introduced in that jurisdiction. In the first reading, Andrew Barr specifically named Morgan Carpenter for his “tireless work”.⁷² In the final reading on 8 June 2023 he stated:

It is particularly thanks to the diligent, passionate and highly intellectual work of advocates involved with Intersex Human Rights Australia, including Steph Lum, Cody Smith, Morgan Carpenter, Bonnie Hart, Mimi Hall and Gabriel Filpi, that this legislation exists.⁷³

IHRA is keen to work with the NSW Ministry of Health and other Departments to implement legislative reforms and deliver psychosocial support services for individuals and families.

⁶⁷ ACT Health, ‘Members of the Assessment Board’ (6 March 2024) <<https://www.health.act.gov.au/services-and-programs/lgbtiq/protecting-rights-people-variations-sex-characteristics/members>>.

⁶⁸ Department of Health, *(I) Am Equal: Future Directions for Victoria’s Intersex Community* (July 2021) <<https://www2.health.vic.gov.au/about/publications/factsheets/i-am-equal>>.

⁶⁹ Department of Health, ‘Victoria’s Intersex Protection System’, *Engage Victoria* (18 June 2023) <<https://engage.vic.gov.au/intersex-protection-system>>.

⁷⁰ NSW Health, *NSW LGBTIQ+ Health Strategy 2022-2027* (2022) <<https://www.health.nsw.gov.au/lgbtiq-health/Pages/default.aspx>>.

⁷¹ ‘IHRA NSW Election Survey’ Letter from Ryan Park, 2 March 2023.

⁷² ‘Daily Hansard: Transcript 22 March 2023’ <<https://www.hansard.act.gov.au/hansard/10th-assembly/2023/HTML/week02/509.htm>>.

⁷³ ‘Daily Hansard: Transcript 8 June 2023’ <<https://www.hansard.act.gov.au/hansard/10th-assembly/2023/HTML/week06/1816.htm>>.

3 Specific issues addressed in this submission

3.1 Sex and sex characteristics

'Sex characteristics' is a finely grained attribute, in comparison to the more coarsely grained concept or attribute of 'sex.' It is intended to operate at the level of body parts, rather than broad classifications of sex.

We do not construct intersex or innate variations of sex characteristics as a sex. We recognise that different ways of determining sex (e.g. phenotype, micturition, gonads, chromosomes, gametes, potential gametes under different material circumstances) or understanding sex (e.g. as biology, legal assignment, or observed status) can have radically different and often conflicting implications for individuals within our population. We encourage respect for the diversity of observed/assigned sex markers and different values and preferences within our population. We recommend alignment of definitions of sex with the Australian Bureau of Statistics Standard on sex, gender, variations of sex characteristics and sexual orientation.⁷⁴ This recognises that sex is typically registered or registered at birth based on observed sex characteristics:

*A person's sex is based upon their sex characteristics, such as their chromosomes, hormones and reproductive organs. While typically based upon the sex characteristics observed and recorded at birth or infancy, a person's reported sex can change over the course of their lifetime and may differ from their sex recorded at birth.*⁷⁵

As a universal attribute, protections from discrimination on grounds of sex characteristics apply not only to people with intersex variations, but also to individuals who have experienced traumatic events or medical interventions that have changed their sex characteristics, such as women who have experienced female genital mutilation.

The Bill diverges from practices elsewhere in Australia by narrowing a proposed protected attribute from 'sex characteristics' to 'variations of sex characteristics', which is further narrowed to refer to people with innate variations (thus excluding acquired variations arising from trauma or from gender affirmation).

Our preference is to always provide for universal protections that protect everyone at risk of discrimination or stigmatisation because their sex characteristics differ from social and clinical norms. We further address this point in our submission below.

3.2 Parental Consent in Children and Young Persons (Care and Protection) Act 1998

IHRA supports the proposal to amend the *Children and Young Persons (Care and Protection) Act 1998* to allow minors who have capacity to consent to medical treatment i.e. to codify the common law principles developed in *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112 and affirmed in *Secretary, Department of Health and Community Services v JWB and SMB (Marion's case)* [1992] HCA 15.

⁷⁴ Australian Bureau of Statistics, 'Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, 2020' (21 September 2023) <<https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release>>.

⁷⁵ Ibid.

The proposed amendment introducing s174A(1) will have the effect of allowing young people (i.e. those aged 16 and 17 years) to consent to medical and dental treatment. Section 174A(2) will allow children (i.e. those under the age of 16) to consent to treatment if they have Gillick capacity and the treatment is in their best interests. It will protect those who provide medical and dental services from liability for trespass as long as the consenting child is able to understand the nature, consequences and risks of the treatment. IHRA believes that minors who have capacity to consent should be given power and authority to consent to medical and dental treatment on their own behalf.

IHRA further supports the principle that the requirement for court authorisation of gender-affirming treatment for Gillick-competent children should be removed in situation where one parents does not consent to treatment, as determined in *Re Imogen*⁷⁶. IHRA endorses concerns that this requirement imposes unnecessary delays and costs associated with provision of treatment. This is an exceptional requirement that does not apply to any other form of medical treatment where a child is able to understand the nature, consequences, and risks of the treatment. IHRA understands that s174A(2)(a) has been drafted in an attempt to avoid this requirement.

However, IHRA believes that **the proposed provision is in need of redrafting** to achieve the desired result. **The current drafting of s174A creates significant problems that go beyond the intended scope of the amendment.**

This impacts our population in a matter that fails to conform to a recommendation made by the Australian Human Rights Commission in respect of the human rights of people with innate variations of sex characteristics such that

‘Laws and practices concerning medical interventions to modify the sex characteristics of people born with variations in sex characteristics should be guided by **a human rights framework based** on the ... principles [of bodily integrity, children’s’ agency, the precautionary principle, medical necessity, and independent oversight].’⁷⁷ (our emphasis)

A proposal to provide unfettered authority to a parent to consent to any and all medical treatment on their child is a deeply concerning move away from a human rights-based decision-making framework.

Arguably, this provision would **allow parental consent to override the refusal** of treatment by a **Gillick-competent child**. It would unarguably **authorise parental consent** to medical treatment that was **opposed by a child who was not yet Gillick competent**. This would be a regression from the child-focused principles of common law.

As it stands, parental consent under s174A(2)(a) is not limited even by the requirement that parents exercise their authority to consent to treatment in the child’s best interests. This needs to be addressed.

The proposed provision will give legal and moral legitimisation for egregious clinical practices of invasive and irreversible medical interventions to alter the sex characteristics of minors, including infants and very young children, to ‘normalise’ their appearance for purported psycho-sexual reasons. Such interventions are routinely performed on children too young to consent, and consent

⁷⁶ *Re Imogen (No 6)* (2020) 61 Fam LR 344.

⁷⁷ Australian Human Rights Commission, *Ensuring Health and Bodily Integrity; Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions(2021)* | (Final Report, 18 October 2021) <<https://humanrights.gov.au/intersex-report-2021>>. Recommendation 1.

is provided by parents or guardians. The interventions are highly contentious and are strongly opposed by international and national human rights experts, advocates, academics, medical professionals and those with lived experience.

In 2016, Forrest J of the Family Court handed down a decision in *Re Carla*⁷⁸ which authorised sterilisation, hormone intervention, and future genital surgery such as vaginoplasty, on a five year old child, and commented favourably on clitoral reduction surgery that had already been performed.⁷⁹ Justice Forrest further found that medical interventions on children with innate variations of sex characteristics, including ‘normalising’ procedures, are ‘therapeutic,’ thereby falling within the bounds of ‘permissible parental authority’ and obviating the need for court authorisation.

In response to this case, and advocacy aimed at addressing human rights concerns with medical treatment on people with innate variations of sex characteristics, the Australian Human Rights Commission established an inquiry into these matters. Following a three-year inquiry, the Commission released a 2021 report⁸⁰ recommending the introduction of a protection scheme to regulate unnecessary and deferable medical interventions aimed at normalising the bodies of intersex children before they are able to consent.

In 2022 the ACT introduced legislation enacting such as scheme to govern the medical treatment of people born with sex characteristics that do not fit the typical definitions for male or female bodies.⁸¹ The Act gives protections to people with many innate variations in sex characteristics. It allows them to make their own decisions about non-essential medical treatments that affect their bodies when they can. Victoria has committed to enact a similar scheme.⁸²

It is important that NSW should legislate for human-rights based regulation of medical interventions on minors with innate intersex variations who are too young to consent. **In the absence of a protective regulatory scheme, the operation of both state and federal law on consent for medical treatment of minors is, for children with innate variations of sex characteristics, permissive and precarious.** The proposal to remove all fetters from parental consent, and to unambiguously validate existing permissive parental consent processes, is deeply problematic.

We acknowledge that, to date, the ‘best interests’ restriction has been inadequate to protect minors with innate variations of sex characteristics from human rights abuses in a medical setting, as noted in the Australian Human Rights Commission report.⁸³ However, **legal reform in Australia should be guided by the need to promote human rights, not to strip back protections, even those that have not been fully effective in protecting all citizens.**

On that basis, IHRA opposes the inclusion of s174A as it is drafted. We recommend that the provision be re-drafted, taking into account the following considerations

1. Consider one means to address the limitations imposed in *Re Imogen* by **restricting the operation of s174A(2)(a) to gender-affirming treatment.** Since this is the only treatment to

⁷⁸ [2016] FamCA 7

⁷⁹ ‘Surgery already performed on Carla has enhanced the appearance of her female genitalia’ *Re Carla* FamCA 7, [2]

⁸⁰ Australian Human Rights Commission (n 77).

⁸¹ *Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023* (ACT)

⁸² Department of Health Victoria, *(I) Am Equal* (2021, State Government of Victoria) Accessed April 9, 2024. <https://www.health.vic.gov.au/publications/i-am-equal>.

⁸³ Australian Human Rights Commission (n 54).

which such restrictions (i.e. the need for consent from both parents) apply, this should be the only circumstance in which the consent of one parent must be explicitly made sufficient.

2. Despite known flaws with the **best interests** test, parental authority should be fettered at least by a need to make decisions in the best interests of the child.
3. Laws touching on consent to medical treatment must be guided by **human rights principles** and implement a framework that is protective of the rights of children, including children with innate variations of sex characteristics
4. NSW must legislate to establish a human rights-based framework to guide medical decision-making on procedures to modify the sex characteristics of a minor without their personal consent. As with legislation in the ACT and proposals in Victoria, this must include criminalisation of unnecessary deferrable medical interventions without personal informed consent, establishment of an independent oversight body.
5. Reforms must also be accompanied by investment in psychosocial support for individuals and families, to enable children and youth to understand and express their own values and preferences for any treatment.

3.3 Supported decision making for consent to medical treatment

IHRA would argue for provisions to promote processes of supported decision-making by individuals about their own treatment, shifting practice towards recognition that everyone needs support to make decisions. Such provisions would require that medical treatment providers take into consideration the evolving capacity of those under 18 years of age. An amendment to facilitate supported decision-making would recognise and implement an understanding of children and youth as rights-holders and emphasise the importance of minors exercising their rights and autonomy.

3.4 Describing and defining people with innate variations of sex characteristics

A matter which IHRA believes requires further amendments is the inconsistent language used to describe and define people with innate variations of sex characteristics in the Bill. The Bill includes at least four different ways to describe this population. To promote clarity and ensure consistency across NSW legislation and laws, we recommend that, unless there are sound reasons for departing from a single standard definition and descriptor, **the Bill should adopt consistent language to describe and define our populations.**

Usage of the term intersex in legislation is not recommended. While ‘intersex status’ has been protected federally under the Sex Discrimination Act since 2013, the purely physical nature of the attribute has been disregarded in common usage, and disregarded even in later bills before the Commonwealth parliament. Conflations of intersex and LGBT populations and their impact on the utility of protections for non-LGBT people with innate variations of sex characteristics mean that we prefer descriptive and universally applicable terminology referring to **‘sex characteristics’**. Specific references intended to refer to people with intersex variations should refer to **‘innate variations of sex characteristics.’**

The inclusion of the word ‘innate’ provides clarity by distinguishing our populations from people with acquired variations of sex characteristics. This can be important in preventing conflation with other populations including people who have undergone gender affirmation processes. Many people acquire variations in sex characteristics, either by choice, (for example cosmetic surgery, gender-affirming medical interventions, or contraception) or as a result of injury, disease, or ageing processes. What defines our population is our lived experience of having innate sex characteristics (such as chromosomes, gonads, reproductive development, or hormones) that differ from medical

norms for female or male bodies. We risk and experience discrimination, stigmatisation and harmful practices because of the ways our bodies are seen as different.

For ample clarity, we further recommend that the legislation should also encompass a **definition of ‘sex characteristics’** based on the Yogyakarta Principles plus 10.⁸⁴ We recommend the definition of sex characteristics recently adopted in Queensland:

sex characteristics, of a person, means the person’s physical features and development related to the person’s sex, and includes—
(a) genitalia, gonads and other sexual and reproductive parts of the person’s anatomy; and
(b) the person’s chromosomes, genes and hormones that are related to the person’s sex; and
(c) the person’s secondary physical features emerging as a result of puberty.

We are informed by colleagues in the Queensland Human Rights Commission that provisions including those relating to this attribute will commence on 29 April 2024.

3.5 Terminology and definitions in the Anti-Discrimination Act

IHRA notes that some other jurisdictions in Australia have adopted a different approach by avoiding the ‘comparator test’ and adopting the ‘less favourable treatment test.’ These jurisdictions have defined ‘sex characteristics’ as the protected attribute. IHRA strongly favours this approach for combatting discrimination, and it would bring the amended legislation into line with the definition and descriptor of the protected attribute in ACT, Northern Territory, Queensland, and Victoria. This broader attribute definition would extend protection as widely as possible, and avoid possible complications around defining which variations are recognised as falling within the definition. For example, some forms of hypospadias have been (at least initially) omitted from protections in the ACT. Furthermore, as noted above, as a universal attribute, protections from discrimination on grounds of sex characteristics apply not only to people with intersex variations, but also to individuals who have experienced traumatic events or medical interventions that have changed their sex characteristics, such as women who have experienced female genital mutilation. A broader and simplified definition would provide certainty, and protect additional people who need to be protected.

However, IHRA understands that the Bill introduces these amendments on an interim basis so that protection can be offered in the short term while major reform of the Anti-Discrimination legislation is in development.

On that basis, IHRA endorses the proposed definition of the protected attribute of ‘innate variations of sex characteristic, together with a legislative definition of ‘sex characteristics’ as outlined above. We hope that the use of the narrow definition will be an interim measure only, until broader protections can be introduced comparable to those in other Australian States and Territories.

3.6 Extending deadlines for Registration of Births

Although IHRA supports the extension of deadlines for birth registration of those born with innate variations of sex characteristics, we are unable to support any contention that extending the time for birth registration will be a substantial or effective means to reduce early unnecessary and deferrable medical interventions on infants and young children to ‘normalise’ their bodies. This view has been

⁸⁴ ‘Yogyakarta Principles plus 10 – Yogyakartaprinciples.Org’ <<https://yogyakartaprinciples.org/principles-en/yp10/>>.

promulgated in other jurisdictions, where it is argued that the pressure of assigning a sex is driving early invasive and irreversible medical interventions. Consultation with our partners internationally has established that measures to extend registrations times simply delay unnecessary and deferrable interventions until the decision to register sex. That is, whether time frames for birth registrations are short or extended, they remain associated with unnecessary interventions. We need to express concern that such measures can distract from the need for more effective and direct regulation to prohibit early interventions.

3.7 Body and Personal Searches

IHRA proposes that the amendments relating to body searches be redrafted to protect all people who believe they are at risk of stigmatisation because of their body features or sex characteristics. Such an approach would mean that the legislation need not refer specifically to either transgender or intersex persons. Instead, reasonable accommodations should be required for any person who believes that their embodiment, particularly embodiment relating to sex characteristics, puts them at risk of stigma or discrimination.

For this approach to be adopted, the amendment should refer merely to ‘sex characteristics’ rather than to ‘variations of sex characteristics’ as a potential focus of stigma in body search circumstances.

4 Submissions per Schedule

4.1 Schedule 1 Amendment of Anti-Discrimination Act 1977

IHRA welcomes the inclusion of variations of sex characteristics as a protected attribute.

IHRA notes that the Bill uses the comparator test of discrimination, which is consistent with other provisions including ss 7, 24, and 38B. IHRA supports these amendments as an interim measure intended to provide protections until more wide-reaching reforms of the legislation can be developed.

The language of ‘variation of sex characteristics’ is helpful and consistent with a widely accepted UN definition.⁸⁵ For ample clarity, the Bill should be amended to include the definition of sex characteristics based on the Yogyakarta Principles plus 10.⁸⁶ Borrowing from these principles, IHRA recommends adopting a clarifying definition of sex characteristics drawn from recent legislation in Queensland:

sex characteristics, of a person, means the person’s physical features and development related to the person’s sex, and includes—

- (a) genitalia, gonads and other sexual and reproductive parts of the person’s anatomy; and
- (b) the person’s chromosomes, genes and hormones that are related to the person’s sex; and
- (c) the person’s secondary physical features emerging as a result of puberty.

IHRA further recommends that descriptor and definition should include the word ‘innate’ before the words ‘variations of sex characteristics’ wherever such reference is intended to refer to people with intersex variations. The absence of these words can result in conflation between people with innate variations and people with acquired variations of sex characteristics.

⁸⁵ OHCHR, ‘Background Note on Human Rights Violations against Intersex People’, *OHCHR* (A Background Note, 2015) <<https://www.ohchr.org/en/documents/tools-and-resources/background-note-human-rights-violations-against-intersex-people>>.

⁸⁶ ‘Yogyakarta Principles plus 10 – Yogyakartaprinciples.Org’ (n 84).

4.2 Schedule 2 Amendment of Births, Deaths and Marriages Registration Act 1995

IHRA does not oppose the introduction of s 16(1)(b) which extends the time limit for birth registration to 180 days where a child is born with an innate variation of sex characteristics.

However, it should be noted that IHRA refutes any contention that this amendment will be a substantial or effective means to reduce early medical interventions on infants and young children to 'normalise' their bodies and bolster sex assignment. This view has been promulgated in other jurisdictions such as Germany, where it was stated that the pressure of assigning a sex is driving early invasive and irreversible medical interventions. Research has demonstrated that such measures have no impact on the number or timing of medical interventions on minors with innate variations of sex characteristics. Whether time frames for birth registrations are short or extended, they will prompt unnecessary interventions. IHRA expresses concern that such measures may distract from the need for more effective and direct regulation to prohibit early interventions.

If the amendment is proposed, then the word 'innate' should be inserted before the words 'variations of sex characteristics.'

IHRA supports the amendments to Part 5A of the Act in relation to altering the sex descriptor on a person's birth certificate.

4.3 Schedule 3 Amendment of Children and Young Persons (Care and Protection) Act 1998

IHRA does not support the proposed introduction of s 174A(2)(a). This provision gives parents authority to consent to medical treatment, unfettered even by the best interests of the child. Arguably, it provides parents with authority to consent to treatment in spite of the considered refusal by a Gillick-competent child.

Amendments affecting parental consent laws must be drafted to protect the human rights of all minors, including those born with innate variations of sex characteristics. The proposed amendment should be redrafted in light of the concerns expressed in section 3 above.

IHRA would recommend provisions which promote the process of supported decision-making by individuals about their own treatment, shifting practice towards recognition that everyone needs support to make decisions. Such provisions would require that medical treatment providers take into consideration the evolving capacity of those under 18 years of age. An amendment to facilitate supported decision-making would recognise and implement an understanding of children and youth as rights-holders and emphasise the importance of minors exercising their rights and autonomy.

4.4 Schedule 4 Amendment of *Children's Guardian Act 2019*

IHRA supports the proposed amendments to the legislation.

4.5 Schedule 5 Amendment of *Court Security Act 2005*

IHRA proposes that the amendments relating to body searches be redrafted to protect all people who believe they are at risk of stigmatisation because of their body features or sex characteristics. Such an approach would mean that the legislation need not refer specifically to either transgender or intersex persons. Instead, reasonable accommodations should be required for any person who believes that their embodiment, particularly embodiment relating to sex characteristics, puts them at risk of stigma or discrimination, or who reasonably fears such stigma or discrimination.

If this approach is adopted, the amendment should refer merely to 'sex characteristics' rather than to 'variations of sex characteristics' as a potential focus of stigma in body search circumstances.

4.6 Schedule 6 Amendment of Crimes Act 1900

IHRA supports the inclusion of innate variations of sex characteristics in Part 3A Div 8 but recommends that the language and definitions of people with innate variations of sex characteristics should be consistent across NSW legislation where possible. IHRA recommends that the word 'intersex' be replaced with the words 'innate variations of sex characteristics' in the headings for Part 3A Div 8 and s93Z. We further recommend that s93Z(5) be amended by omitting the definition of 'intersex status' and replacing that with the definition of innate variation of sex characteristics consistently with the language and definition proposed in Schedule 1.

4.7 Schedule 7 Amendment of Crimes (Administration of Sentences) Act 1999

As outlined in the submission re Schedule 5 amendments, the amendment to provision relating to the conduct of body searches, including s 253J Conduct of Searches, should be drafted to provide protection and require reasonable accommodation to any person who has reasonable grounds to fear that a body search may expose them to stigmatisation or discrimination because of their body features or sex characteristics. This would eliminate the requirement to amend the definitions section 3(1).

4.8 Schedule 8 Amendment of Crimes (Domestic and Personal Violence) Act 2007

IHRA supports the proposed amendments to the legislation, subject to the recommended amendment to use the language and definitions of innate variations of sex characteristics proposed in response to Schedule 1.

4.9 Schedule 9 Amendment of Crimes (Forensic Procedures) Act 2000

As outlined in the submission re Schedule 5 amendments, the amendments to provisions relating to the conduct of body searches, including the amendments to ss 51 and 56, should be drafted to provide protection and require reasonable accommodation to any persons who has reasonable grounds to fear that a body search may expose them to stigmatisation or discrimination because of their body features or sex characteristics. This would eliminate the requirement to amend the definitions section 3(1).

4.10 Schedule 10 Amendment of Crimes (Sentencing Procedures) Act 1999

IHRA supports the proposed amendments to the legislation, subject to the recommended amendment to use the language and definitions of innate variations of sex characteristics proposed in response to Schedule 1.

4.11 Schedule 12 Amendment of Government Sector Employment Act 2013

IHRA supports the proposed amendments to the legislation, subject to the recommended amendment to include the word 'innate' before the words 'variations of sex characteristics' in s63.

4.12 Schedule 13 Amendment of Government Sector Employment (General) Rules 2014

IHRA welcomes the proposed amendment to the Rules which aim to facilitate the employment of people with innate variations of sex characteristics by modifying recruitment and selection processes. IHRA supports the proposed amendments to the Rules, subject to the recommended amendment to use the language and definitions of innate variations of sex characteristics from Schedule 1.

4.13 Schedule 15 Amendment of Law Enforcement (Powers and Responsibilities) Act 2002

As outlined in the submission re Schedule 5 amendments, the amendments to provisions relating to the conduct of body searches, including the amendments to ss 32, 33 and 44, should be drafted to provide protection and require reasonable accommodation to any persons who has reasonable grounds to fear that a body search may expose them to stigmatisation or discrimination because of their body features or sex characteristics. This would eliminate the requirement to amend the definitions section 3.

4.14 Schedule 16 Amendment of Sheriff Act 2005

As outlined in the submission re Schedule 5 amendments, the amendments to provisions relating to the conduct of personal searches, including the amendments to s 7B, should be drafted to provide protection and require reasonable accommodation to any person who has reasonable grounds to fear that a body search may expose them to stigmatisation or discrimination because of their body features or sex characteristics. This would eliminate the requirement to amend the definitions section 3.