August 2022

Submission on "Contemporary Assisted Reproductive Technology and Surrogacy Legislation for Western Australia: Public discussion paper on behalf of the Ministerial Expert Panel"

Intersex Human Rights Australia (IHRA)

1 Contents

2 Introduction

We thank the Department of Health, Western Australia, government for inviting feedback on proposed reforms to regulate assisted reproductive technologies. Intersex Human Rights Australia (IHRA) welcomes the opportunity to propose recommendations in relation to both access to treatment by people with intersex variations, and the application or utilisation of treatment to eliminate embryos and tissues with intersex traits.

2.1 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 systemic advocacy work.

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 staff and 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.

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 (AIS Support Group Australia et al. 2017). 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 the government would find this helpful. This submission may be published.

2.2 Authorship

This submission by IHRA has been written by Morgan Carpenter, M.Bioeth (Sydney), M.InfTech (UTS), executive director of IHRA. It has been supported through review by our board of directors.

Morgan Carpenter is a graduate in bioethics at the University of Sydney School of Medicine. Morgan wrote our submissions to Senate inquiries on anti-discrimination legislation, and involuntary or coerced sterilisation, and also participated in hearings on those inquiries. He participated in the first intersex expert meeting, organised by the UN (Office of the High Commissioner for Human Rights 2019). He was an expert and drafting committee member for the *Yogyakarta Principles plus 10* (Yogyakarta Principles 2017) and a member of an Australian Human Rights Commission expert group on protecting the human rights of

people born with variations of sex characteristics in the context of medical interventions (Australian Human Rights Commission 2021). Morgan has consulted or been a reference group member for the UN Office of the High Commissioner for Human Rights, the World Health Organization, the ACT government, the Australian Bureau of Statistics, NSW Health, and other bodies. His doctorate studies in bioethics at the University of Sydney School of Public Health focus on epistemic injustice, medicine, law and the human rights of people with innate variations of sex characteristics.

His work in relation to assisted reproductive technologies include drafting submissions to the National Health and Medical Research Council (Carpenter and Organisation Intersex International Australia 2014, 2015) and an invited submission to the gene selection committee for Mackenzie's Mission (see Kirk et al. 2020).

3 Summary of recommendations

Our recommendations are as follows.

3.1 Recommendation 1: end harmful practices in medical settings

Instigate legislative reform in WA to prohibit unnecessary medical interventions and provide for independent oversight, building on recommendations by the Australian Human Rights Commission and current proposals in the Australian Capital Territory.

3.2 Recommendation 2: reform existing legislation

Instigate reform to the *Criminal Code* to update the definition of 'gender reassignment' procedures to criminalise such practices on persons unable to personally give informed consent.

3.3 Recommendation 3: subsidise access to treatment

Treatment for marginalised populations – including people with innate variations of sex characteristics – should be subsidised to eliminate historic access barriers.

3.4 Recommendation 4: eliminate discrimination in access to treatment

In line with best practice developments in international human rights law, the *Yogyakarta Principles plus 10*, the *Darlington Statement*, the 2022 report of the Law Reform Commission of Western Australia, and developments in ACT, Tasmania, Victoria, and Queensland, we recommend that the government prohibit discrimination on the *universal* ground of 'sex characteristics', as follows:

> *sex characteristics—*
> *(a) means a person's physical features and development relating to sex; and*
> *(b) includes—*
> *(i) genitalia, gonads and other sexual and reproductive parts of the person's anatomy; and*
> *(ii) the person's chromosomes, genes or hormones that are related to sex; and*
> ***(iii)*** *secondary physical features emerging as a result of puberty.*

3.5 Recommendation 5: eliminate discrimination in use of treatment

The applications and utilisation of assisted reproductive technologies must not discriminate on the basis of sex characteristics.

Intersex traits must not be subject to exemptions from discrimination in the application of reproductive technologies, such as through framing as genetic anomalies, abnormalities or diseases.

4 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 policies, policy proposals, and practices affecting people with innate variations of sex characteristics. We consider these practices to be relevant to discussions about assisted reproductive technologies, to introduce clarity about the population and our experiences of assisted reproductive technologies.

Respondents to a large Australian sociological study of people born with atypical sex characteristics in 2015 (Jones et al. 2016) 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, ovo-testes, 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 selected, in some cases, due to their higher frequency, and in one case due to the existence of relevant recent Family Court decisions – including a 2016 decision adjudicated in Brisbane.

4.1 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 (Warren 2017). 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 androgen insensitivity means that women with complete androgen insensitivity (CAIS) will never 'virilise' ('masculinise') if their gonads are retained or if they take testosterone replacement therapy. Women and girls with partial androgen insensitivity (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 androgen insensitivity may seek virilisation to the extent this is possible. People with 'higher grades' of partial androgen insensitivity have limited capability for virilisation.

Once diagnosed, people with androgen insensitivity are frequently subjected to gonadectomies, or sterilisation. Historically, rates of potential gonadal tumour risk have been overstated. Discussion by a Senate Community Affairs References committee inquiry on involuntary or coerced sterilisation in 2013 found that:

- *The complexity and diversity of cancer risk can become oversimplified, potentially elevating the perceived or communicated risk. Alternative monitoring options may be overlooked.*

- *The committee is concerned that other matters such as 'sex of rearing' or 'likelihood of gender dysphoria' are interpolated into the discussion of cancer risk. This confusion between treatment options to manage cancer risk and treatment options to manage intersex could undermine confidence in the neutrality of those advocating for surgical interventions. (Senate of Australia Community Affairs References Committee 2013)*

At the time of the Senate inquiry, clinical reports suggested a 50% gonadal cancer risk, and the Australasian Paediatric Endocrine Group expressed concern about the questioning of low quality data and clinical reporting that emphasised the highest risks:

> *Some authors have misunderstood the difference between high-risk and low-risk cancer groups within DSD, and in particular, one submission incorrectly implied that the cancer risk for a diagnosis in the highest-risk group ("PAIS with non-scrotal/intra-abdominal testes") was quoted by Warne and Hewitt as being the cancer risk for a diagnosis in the low-risk group ("CAIS")... The implication is that testes or ovaries are being removed from patients with diagnoses at low-risk of cancer, such as CAIS, however this is incorrect (Australasian Paediatric Endocrine Group et al. 2013).*

Our submission had remarked with concern on the following statements that both emphasised the highest level of risk, and associated that risk with a Y chromosome and intra-abdominal testes which are both characteristic of people with CAIS and PAIS:

> *In any DSD ['Disorder of Sex Development'] associated with a Y chromosome, there is an increased risk of germ cell cancer, especially when the testes are intra-abdominal (the risk of seminoma in partial androgen insensitivity is 50% for an intra-abdominal testis) or when there is gonadal dysgenesis. (Warne and Hewitt 2009, 612; cited in Carpenter and Organisation Intersex International Australia 2013)*

Current papers suggest a low gonadal tumour risk of 0.8% associated with the gonads of people with complete androgen insensitivity (Pleskacova et al. 2010). A 2021 paper by Victorian clinicians identifies that new data has significantly reduced known risk levels associated with partial androgen insensitivity:

> *Malignancy risk for intra-abdominal gonads in PAIS was previously estimated at ~50%, hence prophylactic gonadectomy to mitigate this risk was recommended. More recently, data from cohorts with genetic confirmation of underlying diagnosis indicate that while the risk remains at ~30%+ for those with gonadal dysgenesis and intra-*

> *abdominal gonads, it is now estimated to be considerably lower in PAIS than previously attributed (~7% across studies where causative androgen receptor variant was genetically confirmed). (O'Connell et al. 2021, 7)*

Following sterilisation, individuals require hormone replacement to maintain bone health, libido and general health.

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

We are aware of clinical claims that prophylactic sterilisations and genital surgeries on women with androgen insensitivity no longer take place, including claims that such interventions are 'in the past'. For example, the Australasian Paediatric Endocrine Group stated in 2013:

> *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' (Australasian Paediatric Endocrine Group et al. 2013).*

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 androgen insensitivity aged under 50 who have not been sterilised. In 2019, a clinical team in Brisbane published a 'review of adolescent females ages 8 to 18 years of age with DSDs' managed by the Paediatric and Adolescent Gynaecology Service 'over the last 10 years' (Adikari et al. 2019). This period overlaps with the Senate inquiry in 2013. Despite assertions to the contrary made to that inquiry, all children and adolescents with androgen insensitivity reviewed were subjected to gonadectomies, typically in infancy. The review reports that 'In CAIS, bilateral gonadectomies were most often done at infancy'. In relation to all five instances of partial androgen insensitivity reported:

> *'Gonadectomy and feminizing genitoplasty 1 year age.'*
>
> *'Gonadectomy and reconstructive surgery as infant.'*
>
> *'Gonadectomy and surgical creation neovagina as child.'*
>
> *'Gonadectomy and feminizing surgery age 2yo.'*
>
> *'Bilateral gonadectomy.' (Adikari et al. 2019).*

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 androgen

insensitivity (Weidler et al. 2019). We have no data on whether such protocols are being taken up in Western Australia.

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 (for example, Kirkland 2017).

Sterilisation impacts the ability of people with androgen insensitivity to avail of novel assisted reproductive technologies.

4.2 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 (Department of Health 2020).

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 (Meyer-Bahlburg 1990). Research to date has, however, found that a diverse range of potential factors including genetics and environmental factors, may be responsible for sexual attraction (Richards 2017). 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 (Nimkarn and New 2010).*

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

> *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 (Nimkarn and New 2010).*

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 (Senate of Australia Community Affairs References Committee 2013). However, their current status in Australia is undocumented.

These rationales for treatment have proven controversial (Dreger, Feder, and Tamar-Mattis 2012). 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 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 (Victorian Agency for Health Information and Safer Care Victoria 2018)*

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, implying certainty about future gender identity, sexual orientation and normative ideas about future preferences for body morphology (Insight SBS 2017).

No disclosure is made about risks to sexual function and sensation, however, reference is made to vaginal scar tissue in the context of pregnancy and vaginal delivery. The need for such interventions is, however, not indicated or substantiated. Evidence of necessity is lacking, and reliable evidence of good outcomes is lacking. 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 the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization (Lee et al. 2016).*

The fertility of women with CAH is frequently regarded as impaired, although this is sometimes associated with perceived 'psychosocial reasons' such as fewer individuals 'living in a heterosexual relationship' (Hagenfeldt et al. 2008). Pregnancies are often described in the literature as justifying feminising surgical interventions (Houben et al. 2014; Carpenter 2021).

4.3 17-beta hydroxysteroid dehydrogenase 3

Infants with 17-beta hydroxysteroid dehydrogenase 3 (17β-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 (Carpenter 2018a; World Health Organization 2020).*

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 (Australasian Paediatric Endocrine Group et al. 2013).

Additionally, according to a review paper, rates of gender change in persons with 17-beta-hydroxysteroid dehydrogenase 3 deficiency assigned female at birth are '39–64% of cases' (Cohen-Kettenis 2005). 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 17β-HSD3 to be 28%, a 'medium' risk, recommending that clinicians 'monitor' gonads (Hughes et al. 2006). A more recent clinical review published in 2010 reduced risk levels to 17% (Pleskacova et al. 2010) and 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' (Amnesty International 2017). However, like the WHO ICD-11 classification (World Health Organization 2020), current medical journal articles on this trait (for example, Lee et al. 2016) recommend gonadectomy with female gender assignment, and not on the basis of cancer risks.

In 2008, in the Family Court case *Re Lesley (Special Medical Procedure)*, a judge approved the sterilisation of a young child with 17β-HSD3 (Family Court of Australia 2009). 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 Brisbane-based Family Court judge adjudicated the case *Re: Carla (Medical procedure)*. 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]) (Family Court of Australia 2016). 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]):

> *Surgery already performed on Carla has enhanced the appearance of her female genitalia.*

This was a clitorectomy and labioplasty (at [16]), which may sometimes be termed a 'genitoplasty' or 'vulvoplasty'. This statement is quite extraordinary. 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' (World Health Organization et al. 2008). 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 as we discuss later in the Criminal Code of WA, are overly loose. The gender stereotyping evident in *Re: Carla (Medical procedure)* demonstrates a moral hypocrisy in such exemptions.

As with people with AIS, sterilisation impacts the ability of people with 17β-HSD3 to avail of novel assisted reproductive technologies.

4.4 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 (Skakkebæk, Wallentin, and Gravholt 2015). As with other innate variations of sex characteristics, the innate physical characteristics of people with 47,XXY are socially stigmatised. Men with Klinefelter syndrome have poorer socioeconomic outcomes (Skakkebæk, Wallentin, and Gravholt 2015); 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 47,XXY who are not diagnosed may potentially escape some stigma associated with the variation; alternatively, they may either suffer in silence, or clinical signs may be skewed towards those evident in people more likely to be diagnosed. A large study using UK Biobank data found that only 23% of individuals identified had received a prior diagnosis; individuals 'were mostly unrecognized but [47,XXY] conferred substantially higher risks for metabolic, vascular, and respiratory diseases, which were only partially explained by higher levels of body mass index, deprivation, and smoking' (Zhao et al. 2022).

Not all people with 47,XXY sex chromosomes are male (Röttger et al. 2000) but, due to the current medical paradigm that assumes all people with 47,XXY chromosomes are men, women with 47,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.

The fertility of people with 47,XXY is impaired, and surgical interventions early in puberty are sometimes recommended to extract viable sperm (Plotton et al. 2014; Ozveri et al. 2015).

We are supportive of efforts to preserve fertility options for people with 47,XXY. However, we also seek to ensure that adolescents and youth, via approaches that facilitate supported decision-making (Intersex Human Rights Australia and Carpenter 2022), are able to freely assent or consent to treatment.

We are aware of many older people with 47,XXY who have sought treatment to extract viable sperm. We are aware of individuals in heterosexual relationships who have successfully utilised these methods. However, such treatments are costly, and this has proved burdensome and prohibitive for multiple community members.

4.5 Legislation and medical interventions in WA

In this section we raise concerns with legislation in Western Australia that impacts our understanding of discussion and issue papers by the Law Reform Commission, the reforms proposed in these papers, and in particular in consideration of the Commission's view of the meaning of 'gender history' in relation to people with intersex variations.

Section 3 of the Gender Reassignment Act 2000 established a 'gender reassignment board' which grants or refuses 'recognition certificates'. We have reviewed all annual reports by the Gender Reassignment Board currently available online, and we note that all applications are for either 'male to female' or 'female to male' (for example, Gender Reasssignment Board of Western Australia 2008). At present, annual reports on applications are available for the period 2008 to 2020.[1] In these reports, data regarding applications for children are stated only in reports for years between 2008 and 2012 and, in each year, no such applications were reported (Gender Reasssignment Board of Western Australia 2008, 2009, 2010, 2011, 2012).

The Gender Reassignment Act 2000 defines 'gender characteristics' and 'reassignment procedures' as follows:

> ***gender characteristics*** *means the physical characteristics by virtue of which a person is identified as male or female;*
>
> ***reassignment procedure*** *means a medical or surgical procedure (or a combination of such procedures) to alter the genitals and other gender characteristics of a person, identified by a birth certificate as male or female, so that the person will be identified as a person of the opposite sex and includes, in relation to a child, any such procedure (or combination of procedures) to correct or eliminate ambiguities in the child's gender characteristics; (Western Australia 2000)*

Section 22 of the Criminal Code Amendment Act 2004 introduced a criminal prohibition of female genital mutilation, and explicitly excluded 'a reassignment procedure within the

[1] These annual reports are available at https://grb.justice.wa.gov.au/A/annual_reports.aspx

meaning of the Gender Reassignment Act 2000' from the scope of the prohibition (Western Australia 2004).

These provisions are notable for facilitating surgical interventions on children where their sex characteristics ('gender characteristics') differ from gender stereotypes and other normative ideas for female or male bodies. Such practices are routine in Australian hospitals, following diagnosis of an intersex variation. For example, a letter in May 2019 to our executive director Morgan Carpenter from Roger Cook MLA, in his capacity as Deputy Premier and Minister for Health indicates that:

> *Children with variations of sex development are offered individualised medical management and care in the public system at Perth Children's Hospital (PCH), including surgical care if required, as children with any other complex medical condition or variance would. […]*
>
> *Surgery may be indicated for children with variations of sex development for different medical reasons, ranging from reconstructive surgery for variances in development of genitalia, to surgery to minimise high cancer risk in the gonads. (Cook 2019)*

It seems to us that parents of children with intersex variations are offered such treatment, as medical interventions on children with intersex variations frequently take place in children's hospitals before individuals are able to personally consent. Indeed, the Family Court case Re: Carla (Medical procedures) demonstrates that many such procedures deliberately take place before children are able to understand such procedures (Family Court of Australia 2016; Kelly and Smith 2017; Carpenter 2018b; Office of the High Commissioner for Human Rights 2019). The statement about 'reconstructive surgery for variances in development of genitalia' is of grave concern to us. Such interventions have been explicitly condemned in statements to Australia on eliminating harmful practices (Committee on the Rights of the Child 2019; Committee on the Elimination of Discrimination against Women 2018).

These interventions, as described in preceding sections on androgen insensitivity and 17β-HSD3, do not only impact cosmetic appearance, they also impact fertility and ability to avail of novel assisted reproductive technologies, particularly amongst people with XY traits observed and raised female.

4.6 Human rights recommendations on medical practices

In 2021, the Australian Human Rights Commission (AHRC) made 12 recommendations in a report, '*Ensuring health and bodily integrity*' (2021) 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'* (2013). To date, the recommendations of neither report have been implemented.

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 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 (Australian Human Rights Commission 2021, 44 and 74). There is no firm evidence base for current medical practices (Australian Human Rights Commission 2021, 74 and 119; Lee et al. 2016, 176).

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 (Australian Human Rights Commission 2021, 78 and 81).

Additionally, the AHRC report found it necessary to refute a straw man argument, that some advocates want 'a complete moratorium on all genital/gonadal surgery until the individual is able to give informed consent' (Vora et al. 2021; Vora and Srinivasan 2020). 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 (Australian Human Rights Commission 2021, 131).*

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. (Australian Human Rights Commission 2021, 120)*

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 (2017), Committee on the Rights of the Child (2019), the Committee on the Elimination of Discrimination against Women (CEDAW, 2018) and the Committee on the Rights of Persons with Disabilities (2019) 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 procedures (Committee on the Elimination of Discrimination against Women 2018, 26).

The Australian Capital Territory government has committed to reform (Chief Minister, Treasury and Economic Development Directorate 2021) and is expected to present draft legislation for public consultation early this year. The Victorian government has also made commitments to reform (Department of Health 2021). No commitments have been made by the WA government, despite correspondence from IHRA to the Minister for Health.

4.7 Our position and recommendations

Our position is set out in the 2017 *Darlington Statement*, an Australian – Aotearoa/New Zealand intersex community declaration, where we call for a set of interrelated reforms:

- *prohibition as a criminal act of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children [born with variations of sex characteristics] without personal consent*

- *mandatory independent access to funded counselling and peer support [i.e. resourcing of intersex-led organisations to provide peer support, systemic advocacy and services]*

- *appropriate human rights-based, lifetime, intersex standards of care with full and meaningful participation by intersex community representatives and human rights institutions*

- *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 (AIS Support Group Australia et al. 2017)*

Our position is also reflected in the 2017 *Yogyakarta Principles plus 10*, notably Principle 32:

Everyone has the right to bodily and mental integrity, autonomy and self-determination irrespective of sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to be free from torture and cruel, inhuman and degrading treatment or punishment on the basis of sexual orientation, gender identity, gender expression and sex characteristics. No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person. (Yogyakarta Principles 2017)

Principles 32 elaborates the following State Obligations:

A) Guarantee and protect the rights of everyone, including all children, to bodily and mental integrity, autonomy and self-determination;

B) Ensure that legislation protects everyone, including all children, from all forms of forced, coercive or otherwise involuntary modification of their sex characteristics;

C) Take measures to address stigma, discrimination and stereotypes based on sex and gender, and combat the use of such stereotypes, as well as marriage prospects and other social, religious and cultural rationales, to justify modifications to sex characteristics, including of children;

D) Bearing in mind the child's right to life, non-discrimination, the best interests of the child, and respect for the child's views, ensure that children are fully consulted and informed regarding any modifications to their sex characteristics necessary to avoid or remedy proven, serious physical harm, and ensure that any such modifications are consented to by the child concerned in a manner consistent with the child's evolving capacity;

E) Ensure that the concept of the best interest of the child is not manipulated to justify practices that conflict with the child's right to bodily integrity;

F) Provide adequate, independent counselling and support to victims of violations, their families and communities, to enable victims to exercise and affirm rights to bodily and mental integrity, autonomy and self-determination; (Yogyakarta Principles 2017)

Developments in reports by the Australian Human Rights Commission, and the ACT and Victorian governments reflect consideration of these principles.

Action to implement these reforms will, over time, enable more people with innate variations of sex characteristics to avail of novel assisted reproductive technologies.

Recommendation 1: Instigate legislative reform in WA to prohibit unnecessary medical interventions and provide for independent oversight, building on recommendations by the Australian Human Rights Commission and current proposals in the Australian Capital Territory.

Recommendation 2: Instigate reform to the *Criminal Code* to update the definition of 'gender reassignment' procedures to criminalise such practices on persons unable to personally give informed consent.

Recommendation 3: Treatment for marginalised populations – including people with innate variations of sex characteristics – should be subsidised to eliminate historic access barriers.

5 Intersex status and sex characteristics

We thank the Department for recognising the importance of legislative reform to prevent discrimination on grounds of intersex status. In line with recommendations in the 2020 report on reform of anti-discrimination law by the Law Reform Commission of WA we recommend that protections be implemented instead on grounds of sex characteristics (Law Reform Commission of Western Australia 2022). The Commission reported:

> *The Commission supports the use of sex characteristics rather than intersex status, in light of the support for the former term expressed in the stakeholder submissions. The term sex characteristics is also employed in the ACT Act, and the Tasmanian Act, which each adopt a definition similar to section 4 of the Victorian Act.*
>
> ***Recommendation 52***
>
> *A new protected attribute of sex characteristics should be included in the Act.*
>
> ***Recommendation 53***
>
> *Sex characteristics should be defined as a person's physical features relating to sex, including:*
>
> - *genitalia and other sexual and reproductive parts of the person's anatomy; and*
> - *the person's chromosomes, genes, hormones, and secondary physical features that emerge as a result of puberty. (Law Reform Commission of Western Australia 2022, 116)*

We welcome enactment of such protections. In contrast to intersex status, sex characteristics:

- Are universal.
- Can be innate (for example, through genetic traits) or be acquired (for example, through life-preserving medical treatment, trauma, or gender affirmation).
- Cannot be so easily imputed to be a matter of identity, as has been imputed of 'intersex status'.
- Operate at a different, finer, degree of granularity to the coarser, broader concept of sex.
- As an attribute is now an international norm, utilised by international institutions and a growing number of jurisdictions in Australia including ACT (Australian Capital Territory 2020), Tasmania (Tasmania 2019) and Victoria (Victorian Equal Opportunity and Human Rights Commission 2021).
- People with innate variations of sex characteristics inherently have combinations of sex characteristics that vary from gender stereotypes.

5.1 Our position and recommendation

Enactment of protections from discrimination on grounds of sex characteristics is in line with the *Darlington Statement* and the *Yogyakarta Principles plus 10*. The *Darlington Statement* (AIS Support Group Australia et al. 2017) issues direct calls for reforms to anti-discrimination legislation including:

> *9. We call for **effective legislative protection** from discrimination and harmful practices on grounds of **sex characteristics**.*
>
> *57. We call for policies in educational institutions and employment to recognise that some people born with intersex variations may benefit from **accommodations and reasonable adjustments**, including special needs requirements, workplace adjustments, job access assistance, and provisions for medical leave. (AIS Support Group Australia et al. 2017)*

In November 2017, the *Yogyakarta Principles* on the application of international human rights law to sexual orientation and gender identity were updated with a Supplement on the application of international human rights law in relation to sexual orientation, gender identity, gender expression and sex characteristics. A universal definition of 'sex characteristics' is provided by that *Yogyakarta Principles plus 10*:

> *each person's physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty (Yogyakarta Principles 2017)*

We expect this definition to continue to be widely adopted in international, national and state law, in the same way that the 2007 Principles have led to the widespread adoption of consistent definitions of 'sexual orientation' and 'gender identity' (O'Flaherty and Fisher 2008; Carpenter 2021).

Recommendation 4: In line with best practice developments in international human rights law, the *Yogyakarta Principles plus 10*, the *Darlington Statement*, the 2022 report of the Law Reform Commission of Western Australia, and developments in ACT, Tasmania, Victoria, and Queensland, we recommend that the government prohibit discrimination on the *universal* ground of 'sex characteristics', as follows:

> ***sex characteristics—***
> ***(c) means a person's physical features and development relating to sex; and***
> ***(d) includes—***
> ***(iv) genitalia, gonads and other sexual and reproductive parts of the person's anatomy; and***
> ***(v) the person's chromosomes, genes or hormones that are related to sex; and***
> ***(vi) secondary physical features emerging as a result of puberty.***

6 Discrimination in the use of assisted reproductive technologies

The discussion paper makes conflicting remarks in relation to discrimination on grounds of intersex status. It suggests that discrimination in access to treatment should be prohibited, but constructs a loophole permitting discrimination in the utilisation or application of assisted reproductive technologies. The paper states:

> *The current HRT Act permits ART procedures to be carried out to the benefit of single women or opposite sex couples where they are unable to conceive or carry a pregnancy. This eligibility restricts access to ART for some people on the basis of sex, relationship status, gender identity, intersex status and sexual orientation.*
>
> *It is proposed that access to ART is expanded to everyone (regardless of sex, relationship status, gender identity, intersex status or sexual orientation) who meet the below criteria:*
>
> > *a) the person or couple are unlikely to become pregnant other than by an ART procedure.*
> >
> > *b) the person or couple are unlikely to be able to carry a pregnancy or give birth to a child without an ART procedure.*
> >
> > *c) the person is at risk of transmitting a genetic abnormality or genetic disease to a child born as a result of a pregnancy conceived other than by an ART procedure, including a genetic abnormality or genetic disease for which the person's partner is the carrier.*
>
> *This would expand ART access to females who face impending infertility, single men, same-sex couples, transgender people and intersex people. (Department of Health (WA) 2022, 5–6)*

Assisted reproductive technologies are already available to some intersex people, including some youth with 47,XXY and some women with intersex traits and reproductive tissues if they are in heterosexual relationships. The language in the paper unfortunately suggests a lack of comprehension of the intersex population, such that the Departmental authors are surprisingly unaware of attitudes and clinical statements that frame intersex variations consequentially as 'disorders of sex development' (Hughes et al. 2006; Davis 2011; Carpenter 2018a).

Even more concerningly, provision (c) reproduces a loophole in existing legislation that permits the elimination of foetuses and embryos with intersex traits.

Current clinical practices indicate that clinicians may present the birth of a child with an intersex variation as an adverse outcome to be prevented. In our view, people with intersex variations are capable of living happy, fulfilling lives and such beliefs are predominantly grounded in stigmatising views about bodily diversity. The rationales for the elimination of intersex traits via genetic screening technologies frequently mirror the rationales for

postnatal genital and gonadal surgeries – that is, they are grounded in the idea that it is wrong to grow up with atypical sex characteristics.

In many cases, intersex traits are considered suitable for elimination from the gene pool, and they may be offered to families and siblings of individuals with an identified intersex trait. IVF and other forms of genetic screening may eliminate sex chromosome variations. Examples include:

- Androgen insensitivity, 5α-reductase deficiency (5α-RD2) and 17β-hydroxysteroid dehydrogenase 3 deficiency (17β-HSD3) can be determined via specific tests that may be proposed if siblings or family members have a relevant diagnosis. These traits appear to be considered suitable for elimination, but there are no substantive health or quality of life factors justifying elimination other than risk of forced medical interventions (for which we read risk of stigmatisation) to underpin these rationales (Carpenter 2018a).

- Sex chromosome variations, such as 47XXY (Klinefelter) and 45X0 (Turners) can be established via IVF and other tests, with high rates of terminations increasingly reported in discussions with genetics counsellors for 47,XXY. In our view, these are inconsistent with the health risks associated with the trait (Zhao et al. 2022). These traits are sometimes associated with cognitive and physical health issues, for example, 47XXY is associated with hypogonadism and a range of other issues, but there are low overall rates of diagnosis for this variation (Gravholt et al. 2018; Herlihy et al. 2011). Sex chromosome variations are also associated with higher rates of miscarriage.

- In the case of congenital adrenal hyperplasia, prenatal treatment with dexamethasone may be offered to minimise physical expression of the trait. This treatment is controversial as it has been directly associated with consequences for the future child's behaviour and sexual orientation (Nimkarn and New 2010; Dreger, Feder, and Tamar-Mattis 2012), cognitive development (Dreger, Feder, and Tamar-Mattis 2012; Hirvikoski et al. 2012) and fertility (Poulain et al. 2012). Siblings and other family members may also be offered genetic screening. Congenital adrenal hyperplasia can be associated with salt wasting, which is potentially fatal if not treated – genital surgeries are incapable of addressing this issue.

- A 2016 Australian study reported an increase in the percentage of individuals with intersex variations receiving a genetic diagnosis from 13% to 35% (Eggers et al. 2016).

There is a long history of clinical research into the prenatal or genetic origins of sexual orientation and gender identity, much of it drawing directly upon research on variations of sex characteristics or problematising sexual orientation or gender identity in people with intersex variations (for example, Meyer-Bahlburg 1990; Nimkarn and New 2010). These issues consequently have implications for other sexual and gender minorities (Sparrow 2013; Behrmann and Ravitsky 2013; Davis 2013).

While the NHMRC ethical guidance suggests that quality of life be considered in determining the seriousness of a 'genetic abnormality' and assessing whether or not it should be eliminated (National Health and Medical Research Council 2017). In Victoria, the 2019 Gorton review of assisted reproductive treatment in that jurisdiction heard concerns about genetic deselection and asserted:

> *Stakeholders were also concerned about the potential deselection of embryos with some intersex variations. While the Act prohibits selection on the basis of sex, there were concerns that some intersex variations are classified as serious genetic abnormalities and screened out on that basis. While clinicians informed the Review that this deselection is not happening in practice, these concerns do highlight the need for more information regarding how and why embryos are chosen for implantation above others, to ensure that intended parents are fully informed about their fertility journey. Further consultation with people with intersex variations may be required to fully understand this issue (Gorton 2019)*

This appeal to clinical informants is troubling, especially in the light of evidence of practices that are clearly and well-documented by clinicians in the field. For example, prior and subsequent book chapters by Amor (2012, 2020) at the Royal Children's Hospital Melbourne discuss the possibility of parents having a child with a "DSD" as a matter of "risk estimation", including "risk of transmission from an affected parent to a child" or risk of having an "affected child". Amor omits any discussion of quality of life, and presents deselection as a value-neutral option where diagnosis of a child with a "DSD" presents parents with "difficult choices about future pregnancies" (Amor 2012, 2020). This framing is highly prejudicial. Further, O'Connell and other Victorian clinicians refer in a 2021 paper to 'reproductive planning for the family' as a rationale for establishing a genetic diagnosis (O'Connell et al. 2021, 6). We have no comparable data on practices in Western Australia, but we note that current and proposed legislation sets parameters that facilitate such practices.

As prenatal and preconception screening become cheaper and more widespread, we fear that more and more prospective parents will unnecessarily rule out having a child with an intersex variation. We know that parents respond to the information they are provided and the context that it is provided in. We know that access to affirmative information and peer and family support remains extremely limited.

The gene review committee of Mackenzie's Mission preconception screening program has determined which genetic traits should be included in a pilot screening program in Australia. Following an invited submission by bioethicist and IHRA executive director Morgan Carpenter, the committee determined that non-syndromic intersex traits should not be subject to screening:

> *Adverse impacts associated with DSD tend to draw on societal norms rather than intrinsic clinical features. This includes the experience of stigma, discrimination and other harms arising from a person's body not conforming to norms of gender or biological sex. In particular, concerns were raised about the use of medical intervention to "fix" children born intersex without sound clinical rationale. There was also*

discussion of the message that inclusion of DSD in an carrier screening panel is premature, not least because of ongoing ethical debate regarding selecting against DSD. Thus, DSD that occurs in the absence of other serious clinical features did not meet our criteria for inclusion (Kirk et al. 2020).

In our view, the determination of the gene review committee of Mackenzie's Mission provides for a better approach.

6.1 Our position and recommendation

In our view, it would be inconsistent and tokenistic to prohibit discrimination only in access to assisted reproductive technologies, and not the use and application of such technologies.

Given the role of social stigma rather than 'intrinsic clinical features' in framing intersex traits as undesirable, we recommend that loopholes permitting the elimination of embryos and tissues with intersex traits on grounds of 'genetic abnormality or genetic disease' be closed and eliminated.

In line with the *Darlington Statement* and the Yogyakar*ta Principles plus 10*, we call for an end to discrimination in the use and application of assisted reproductive technologies. The *Darlington Statement* remarks:

25. We call for an end to the use of IVF and other forms of genetic selection to de-select variations of sex characteristics.

26. We call for access to reproductive services and fertility counselling for all intersex people, with protection of our reproductive autonomy, regardless of whether or not our capacity for fertility is considered to be in line with our legal sex. (AIS Support Group Australia et al. 2017)

The *Yogyakarta Principles plus 10* State Obligations on 'Relating to the Rights to Equality and Non-Discrimination (Principle 2)', specify that States should:

L) Combat the practice of prenatal selection on the basis of sex characteristics, including by addressing the root causes of discrimination against persons on the basis of sex, gender, sexual orientation, gender identity, gender expression and sex characteristics, and by carrying out awareness-raising activities on the detrimental impact of prenatal selection on these grounds;

M) Take measures to address discriminatory attitudes and practices on the basis of sex, gender, sexual orientation, gender identity, gender expression and sex characteristics in relation to the application of prenatal treatments and genetic modification technologies (Yogyakarta Principles 2017).

These share the same principles as a United Nations interagency statement on preventing gender-biased sex selection (Office of the High Commissioner for Human Rights et al. 2011).

As with gender-biased sex selection, these statements and priorities are underpinned by a right to freedom from discrimination established in international human rights conventions.

The *Yogyakarta Principles plus 10* also call for access to safe, affordable and effective contraception, and to abortion 'without discrimination based on sexual orientation, gender identity, gender expression or sex characteristics' (Yogyakarta Principles 2017).

Recommendation 5: The applications and utilisation of assisted reproductive technologies must not discriminate on the basis of sex characteristics.

Intersex traits must not be subject to exemptions from discrimination in the application of reproductive technologies, such as through framing as genetic anomalies, abnormalities or diseases.

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