



February 2022

Submission on reform of the *Anti-Discrimination Act 1991*

Intersex Human Rights Australia (IHRA)



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2 Introduction

We thank the Queensland Human Rights Commission for developing the Discussion Paper on proposed amendments to Queensland *Anti-Discrimination Act 1991*. Intersex Human Rights Australia (IHRA) welcomes the opportunity to propose and justify 12 recommendations.

At present, the Queensland government sends messages that we can be disregarded, sterilised, un-resourced, and constructed as something other'; it sends messages that it doesn't want intersex people to be born, will not protect us from harmful practices in medical settings, doesn't want us working with children, doesn't want us playing sport, and wants religious institutions and insurance companies to be able to lawfully discriminate against us. These are damaging and stigmatising messages, evident in the *Anti-Discrimination Act 1991* ('the Act') and its omissions, that cause profound harm. Some of these messages are evident in the Commission's Discussion Paper itself.

We hope that these concerns can be addressed in proposals for revision of the Act.

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 Commission 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, with contributions by Dr Aileen Kennedy, secretary of the board and law lecturer at UNE. It has been supported through review and feedback 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, 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.

Aileen Kennedy has a doctorate in health law from the University of Technology Sydney, focusing on the influence of neuroscience in regulating sex and gender surgery on children. A lecturer in law at the University of New England, Aileen's research focuses on the law relating to cosmetic surgery, female genital mutilation, voluntary amputation and other non-therapeutic body modifications. A focus of her research is on legal and ethical issues relating to biotechnological innovation such as assisted reproductive technology, genetics and neuroscience. She is interested in feminist theory, particularly theories of embodiment. Aileen was also 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).

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 policies, policy proposals, and practices affecting people with innate variations of sex characteristics. We consider these practices to be relevant to discussions about discrimination, including in relation to discrimination in medical settings, and in relation to an exemption proposed in sport.

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, müllerian agenesis, vaginal agenesis), micropenis, mosaicism involving sex chromosomes, müllerian (duct) aplasia, ovario-testes, progestin induced virilisation, Swyer syndrome, Turner's syndrome/XO (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 recent Family Court decisions – including a 2016 decision adjudicated in Brisbane.

3.1 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 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 AIS (Pleskacova et al. 2010). Following sterilisation, individuals require hormone replacement to maintain bone health, libido and general health.

Women with complete AIS report assumptions behind medical intervention that include the idea that women 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 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' (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 AIS aged under 50 who have not been sterilised. 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 (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 AIS (Weidler et al. 2019). We have no data on whether such protocols are being taken up in Queensland or the rest of 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).

Historically, some women with complete AIS were excluded from competitive sport following chromosomal tests. Some women with partial AIS are remain excluded. Women in such situations often have no prior knowledge of their variation, and suffered humiliation, loss of career and, in at least one documented case, home and relationship (Martínez-Patiño 2005).

Chromosomal testing was abandoned as an unjust method of determining sex before the end of the twentieth century (Simpson J et al. 2000) before being reintroduced by World Athletics in recent years (International Association of Athletics Federations 2019). That reintroduction of testing affects women with partial AIS and some other variations such as 17-beta hydroxysteroid dehydrogenase 3 deficiency, 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' (Longman 2021; BMJ Publishing Group Ltd and British Association of Sport and Exercise Medicine 2021).

3.2 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 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 (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).

3.3 17-beta hydroxysteroid dehydrogenase 3

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 (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 17 β -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 17 β -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 17 β -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 clitorrectomy 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 in the Criminal Law of Queensland, which

permits 'surgical procedure[s] to give a person the genital appearance of a particular sex, whether male or female' (Queensland 2000). The gender stereotyping evident in *Re: Carla (Medical procedure)* demonstrates a moral hypocrisy in such exemptions.

3.4 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 (Skakkebaek, Wallentin, and Gravholt 2015). 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 (Skakkebaek, 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 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.

Not all people with XXY sex chromosomes are male (Röttger et al. 2000) 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.

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 (Butler 2003). 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' (Butler 2003).

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, or all people with intersex variations, wish to be marked as neither female nor male.

3.5 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 non-discrimination.

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 human rights violations against intersex people include harmful stereotypes, stigma, taboos, and pathologization (i.e. treating intersex persons as necessarily ill or disordered) (Office of the High Commissioner for Human Rights 2019)

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’ (Jones et al. 2016).
- 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 (Jones et al. 2016).
- 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 (Intersex Human Rights Australia 2016; Carpenter and Zavros-Orr 2019).

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 (Office of the High Commissioner for Human Rights 2019, 4–5)

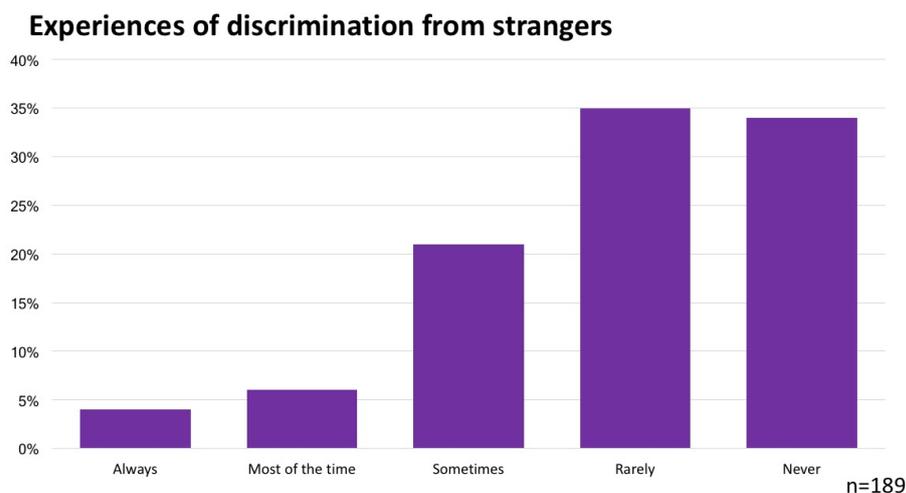
This lies behind our rejection in the *Darlington Statement* of associations between intersex variations and exclusion from, or inclusion in, any category of sex as a population (AIS Support Group Australia et al. 2017). We support choice at an individual level where this does not impact the rights of 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 (Office of the High Commissioner for Human Rights 2019, 5).

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

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.¹



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 (Jones et al. 2016). 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.

¹ We provide recommendations about good practice at <https://ihra.org.au/forms>

3.6 Medical practices in Queensland

Albeit without direct access to detailed hospital records, we have been able to identify patterns in, and data on, Queensland medical practice that gives rise to serious concerns regarding discrimination and experience of harmful practices. In 2012, the Queensland Department of Communities asserted that:

Previously it was an accepted practice to assign the external genitalia of a child during their childhood, often through surgical intervention ... Research and investigation now advises against any irreversible or long-term procedures being performed on intersex children, unless a condition poses a serious risk to their health (Department of Communities 2012)

This does not accord with evidence from the Family Court case *Re: Carla (Medical procedure)* which was adjudicated in Brisbane, nor does it accord with evidence of actual clinical practices.

Early surgical and hormonal interventions to modify the appearance and function of atypical sex characteristics remain routine in Australia. For example, a 2020 paper in the *Australian Journal of General Practice*, identifies ‘surgical options’ as a factor in determining ‘sex assignment’ in situations of doubt (Vora and Srinivasan 2020).

In 2018, Morgan Carpenter published a compilation of data sources including Medicare procedure numbers over the period between 2002/3 and 2014/5, finding that there was limited national evidence of change to clinical practices (Carpenter 2018b)

It also does not accord with evidence on treatment of 24 adolescents treated at a Paediatric and Adolescent Gynaecology (PAG) Service in Brisbane. A poster presentation at the 2019 Annual Scientific Meeting of RANZCOG by Adikari, O’Brien, Bagchi and Kimble outlines a ‘retrospective review of adolescent females ages 8 to 18 years with DSDs presenting to the Queensland PAG Service, Brisbane Australia over the last 10 years’.² It identifies how:

The most common reasons for referral were primary amenorrhea, hormone replacement, and vaginal dilation and the average age initial review 17 years, 3 months. 5 adolescents were unaware of their diagnosis prior to referral and assessment, with 13 diagnosed in infancy with ambiguous genitalia [sic] or hernia. (Adikari et al. 2019)

The adolescents had frequently been subjected to early unnecessary interventions:

Gonadectomy was performed in all cases, except in the Turner’s variant. In CAIS, bilateral gonadectomies were most often done at infancy. (Adikari et al. 2019)

² Due to the nature of the service, focused on gynaecology, the cohort excludes persons observed/assigned male.

The presentation gives case descriptions for 18 persons, including the following subset of surgical practices of grave concern:

Gonadectomy and feminizing genitoplasty 1 year age. Vaginal dilatation. [PAIS]

Gonadectomy and genitoplasty [sic] as infant. Pubertal induction and HRT. Vaginal Dilatation. [Mixed gonadal dysgenesis]

Gonadectomy and reconstructive surgery as infant. Pubertal induction and HRT. Vaginal dilatation. [PAIS]

Gonadectomy and surgical creation neovagina in adolescence. Pubertal induction and HRT. Vaginal dilators. [5 alpha reductase deficiency – age of surgery in adolescence and the person providing consent are not disclosed]

Gonadectomy and surgical creation neovagina as child. Pubertal induction and HRT. Vaginal dilators. [PAIS]

Gonadectomy and feminizing surgery age 2yo. Pubertal induction and HRT. Vaginal dilatation. [PAIS]

Bilateral orchidectomy and hernia repair aged 12. Pubertal induction and HRT. Vaginal dilatation. [17β-HSD3]

Bilateral gonadectomy. Pubertal induction and HRT. Vaginal dilatation. [PAIS] (Adikari et al. 2019)

These case descriptions exclude cases of people with congenital adrenal hyperplasia, where early genitoplasties, and sometimes vaginoplasties, appear to be routine in order to make children's bodies fit gender stereotypes for appearance and function.

The Australasian Paediatric Endocrine Group of clinicians (APEG) has sought to take management of intersex cases out of court jurisdiction and into internal clinical processes that lack transparency and provide no possibility of scrutiny, however flawed (Thomsett and Warne 2021). In a presentation in 2013, Garry Warne of APEG commented:

- *Fear of litigation leads doctors and hospital insurers in Brisbane to delegate decision making about surgery for infants and children with intersex conditions to the Family Court*
- *Court supports proposed surgery in every case*
- *Costs are considerable, families are stressed*
- *Legal precedents are set which are binding throughout Australia*
- *The focus is on protecting the hospitals, not on protecting the patients' best interests*

- *Chaos ensues. APEG convenes national meeting, involving the Chief Justice and former Chief Justice. All agree that court involvement is regrettable. (Warne 2013, 22)*

While we agree that the Family Court has been unable to provide independent and effective oversight, we characterise this situation as a form of institutional capture. A shift towards internal consideration of cases by multidisciplinary teams, without transparency, is more complete in New South Wales and Victoria, with subsequent relevant Family Court cases only in Queensland (Family Court of Australia 2016, 2017). Multidisciplinary teams do not provide assurance of treatment that meets fundamental human rights norms. The Australian Human Rights Commission report (2021) and *Darlington Statement* propose alternative forms of independent oversight.

Multi-million dollar public research funds have been spent on the determination of genetic causes of intersex traits, some of it justified on the basis of ‘psychological trauma’ (University of Queensland Undated). National Health and Medical Research Council guidelines on the use of assisted reproduction technologies treat intersex variations in the same way as other traits considered to be genetic disorders: permitting elimination only when a ‘genetic condition, disease or abnormality’ would ‘severely limit the quality of life of the person who would be born’ (National Health and Medical Research Council 2017). Despite justifications referring to psychological trauma, the role of medical practices and stigma in constructing trauma has been poorly considered in clinical settings. Peer and family support for people with intersex variations is almost entirely unfunded, prior to a pilot project shortly to commence later in 2022.

3.7 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 commitment has yet been made by the Queensland government.

3.8 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.

Recommendation 1

Instigate reform to health legislation in Queensland to prohibit unnecessary medical interventions and provide for independent oversight, building on forthcoming proposals in the Australian Capital Territory.

Recommendation 2

Instigate reform to the *Criminal Law Act* to update the definition of 'sexual reassignment' procedures to 'give a person the genital appearance of a particular sex' to criminalise such practices on persons unable to personally give informed consent.

4 Question 26: gender identity

Intersex is not a gender identity. The term relates to a set of innate physical characteristics affecting chromosomes or development of genitals, gonads and anatomy. However, the *Anti-Discrimination Act 1991* is purported to have referred to intersex people within an attribute of gender identity. The Act was amended in the *Discrimination Law Amendment Act 2002* to refer not to intersex but to ‘indeterminate sex’:

gender identity, in relation to a person, means that the person—

(a) identifies, or has identified, as a member of the opposite sex by living or seeking to live as a member of that sex; or

(b) is of indeterminate sex and seeks to live as a member of a particular sex.

Similar provisions regarding ‘indeterminate sex’ exist in anti-discrimination or equal opportunity legislation in New South Wales and, until 2021, in Victoria.

4.1 Lacks a basis in actual processes of sex determination

We have never been able to ascertain the relevance of the attribute to the lives of people with intersex variations, given that we are invariably observed or assigned female or male, at birth. We take the term ‘particular sex’ to refer to that female or male birth registration, but this is not clear. Who determines whether or not someone observed or assigned female or male at birth is ‘of indeterminate sex and seeks to live as a member of a particular sex’? Who has agency to ‘seek to live’ in this way and what decisions do they make to do that? On what basis is their birth sex disregarded?

The child identified in a Family Court case adjudicated in Brisbane with the pseudonym Carla, in the previous section, was not described as ‘of indeterminate sex’. Carla was observed as female at birth, ‘with the external appearance of a female child’ and subsequently subjected to clinical tests; Carla was described by the judge as having a ‘genetic disorder’, specifically a named ‘sexual development disorder’, as being ‘genetically male’, and described as having had surgery that ‘enhanced the appearance of her female genitalia’ (Family Court of Australia 2016; Kelly and Smith 2017; Carpenter 2018a). This intervention was not described as a reassignment; the child was already observed female at birth. A preschool child, Carla did not have age or agency to freely express any gender identity at the time of the judgment.

4.2 Lacks a basis in community engagement or acceptance

We note that the Explanatory Memorandum for the *Discrimination Law Amendment Bill 2002* mentions the term intersex on one occasion, in reference to this attribute and remarking that the bill brought Queensland into line with other jurisdictions (Parliament of Queensland 2002b). The Explanatory Memorandum also notes that no community consultation occurred.

Intersex Human Rights Australia did not form until 2009; we registered as a not-for-profit company only in 2010. Intersex Peer Support Australia, also known as the Androgen Insensitivity Syndrome (AIS) Support Group Australia, became an incorporated association in 2001. Their submissions in this period consistently reject any association of intersex variations with an attribute termed gender identity. Unfortunately, as a volunteer-run community organisation, not all records are available across the full life of that organisation. However, Hansard records that members of the Legislative Assembly received a letter from the AIS Support Group Australia. Only two speakers mentioned this letter in their statements to the Assembly during the second reading of *Discrimination Law Amendment Bill 2002* on 28 November 2002. Liz Cunningham (Independent) remarked:

I want to quote from a document I received—and I am sure all members received it—from the Androgen Insensitivity Syndrome Support Group Australia, which was not a group that I had heard of before. The document states—

The Androgen Insensitivity Syndrome Support Group ... is an international support group based in Australia that provides support and information for those affected by intersex conditions. Intersex conditions are those long-established medical conditions where a child is born with reproductive organs, genitals and/or sex chromosomes that are not exclusively male or female. The previous word for intersex is hermaphrodite.

...

People with intersex conditions are not transgender. Most people with intersex conditions identify in the gender they are raised and have no gender identity issues. Those that do have issues with gender identity is a result of an incorrect choice by doctors at birth. This is, of course, an honest mistake on the part of doctors who do their best to assign a sex of rearing in a child whose sex is unclear. These people should not be discriminated against because of their biological condition.

...

We would appreciate open dialogue between ourselves, the medical community and the proposers of this Bill prior to its ratification in the Queensland Parliament.

I would be interested to know whether this dialogue has occurred (Hansard 2002, 5076).

Lawrence Springborg (National) remarked:

I also note that the intersex association has sent information to all members of parliament to the effect that it disagrees with being bundled in with transgenders and that its issues are quite separate. That association would like this legislation held over until those issues can be addressed (Hansard 2002, 5017).

Today we would acknowledge that some people with intersex variations who transition gender understand themselves as transgender, in addition to having an innate variation of sex characteristics.

While these extracts from Hansard are limited, they make clear that intersex variations and gender identity are two distinct issues that should not have been conflated in the legislation, and the bill was not supported by our sibling organisation at the time.

An explanatory memorandum for amendments in committee outlined some technical changes, proposals for religious exemptions, and identified consultation with a range of bodies that did not include any recognised intersex-led or intersex-competent organisation (Parliament of Queensland 2002a).

4.3 Grounded in misconceptions and errors

Despite lobbying by our sibling organisation, a Queensland Parliamentary Library research brief dated 2003 and titled 'Protecting Transgender Rights under Queensland's Discrimination Law Amendment Act 2002' mentions intersex people as a type of transgender person. The single substantive remark refers to a resource by the Australian Civil Liberties Union that:

defines 'transgender' as 'a non-medical term adopted by people with gender identity issues which are not a matter of sexual orientation or preference, but a subjective conviction as to the gender they feel themselves to be, regardless of their chromosomal or birth sex'. They identify the main divisions within this group as being:

[...]

- *intersex people (formerly known as 'hermaphrodites') are born with indeterminate sexual characteristics. There are a large range of medical conditions associated with this group, the most common of which is 'androgen insensitivity syndrome', either complete or partial. Many intersex people feel that they have unique problems which warrant their being known as a separate 'intersex' group rather than 'transgender'. (Easton 2003)*

Intersex is not a matter of 'subjective conviction'. What are described as 'indeterminate sexual characteristics' do not imply an indeterminate sex assigned or observed at birth. Many people with intersex variations have traits that are characterised at times other than birth. The errors and superficiality in this analysis, and lack of acknowledgement of processes of sex registration, give rise to grave cause for concern.

We note that the Commission's discussion paper contains no information on utilisation of the attribute, and we are unable to endorse or support the attribute of 'gender identity' as a meaningful or accurate form of inclusion.

4.4 Our position and recommendations

The current consultation is an opportunity to wipe the slate clean, and respond to community expectations.

We do not agree that prior language should be or have been assumed to refer to people with intersex variations. This language was opposed by our community organisation at the time, and it remains opposed as inappropriate and misleading today.

We do not agree that an appropriate attribute developed through community engagement – such as ‘sex characteristics’ – should inherit regulations or exemptions that apply to gender identity.

Recommendation 3

Reforms to the *Anti-Discrimination Act 1991* to respond to discrimination against people with innate variations of sex characteristics should start from a clean slate. A new attribute of ‘sex characteristics’ and other provisions should not inherit exemptions or regulations from prior versions of the Act.

The definition of gender identity should be amended to delete all reference to persons ‘of indeterminate sex’ and to bring the definition into line with current best practice.

Recommendation 4

The definition of ‘gender identity’ should be amended in line with the *Yogyakarta Principles (2007)*.

5 Questions 31 and 50: irrelevant medical record, and impairment

Some community members have reported to us requirements that they pay loaded insurance premiums for life insurance cover. This is a form of discrimination due to genetic test results.

Tiller and others reported in 2020 on a survey of 174 Australian consumers with genetic traits that predispose them to cancer. They found that ‘both legal (permitted under current regulation) and illegal discrimination is occurring’:

Of those experiencing difficulties, 50% (32/64) had no prior history or symptoms of cancer, and had undertaken risk reduction through surveillance and/or preventative surgery. Seventy-seven percent (49/64) reported difficulties related to life insurance. Follow-up telephone interviews with four respondents further described cases of apparent illegal breaches. All reports of discrimination identified were, to our knowledge, previously unreported in the literature. The number of cases suggests a systemic problem with the Australian life insurance industry. We support calls for government oversight of the inherently conflicted model of industry self-regulation in Australia, and an immediate ban on the use of genetic test results in insurance underwriting. (Tiller et al. 2020, 108)

Rothstein and Brothers note that discrimination on grounds of genetic information ‘discourage people from undergoing potentially beneficial genetic testing’ (Rothstein and Brothers 2020, 2101). Trends towards greater availability of genetic screening, including preconception screening, mean that higher proportions of the population are likely to have identified genetic risks.

Some intersex variations are associated with evidenced high risks of gonadal cancer. Early surgical intervention to remove gonads currently appears to be the norm, even in relation to traits where there is little evidence, or risk levels are not high (Kelly and Smith 2017; Carpenter 2018a). In addition, some individuals have reported unduly high insurance premiums to us even following surgery.

In our view, genetic discrimination does not necessarily fall within a conception of ‘irrelevant medical record’. The Commission’s discussion paper notes that the concept of ‘irrelevance’ is undefined in Tasmanian and Northern Territory law. The Commission also notes that ‘impairment’ includes ‘an attribute that a person had in the past’ (Queensland Human Rights Commission 2021, 102). However, subdivision 2 of the Anti-Discrimination Act 1991 permits discrimination on the basis of age or impairment when ‘based on reasonable actuarial or statistical data’. In our view, the growth of genetic screening is expanding the population subject to such exemptions and this is not reasonable.

5.1 Our position and recommendation

Enactment of protections on grounds of genetic discrimination are in line with the *Darlington Statement*. The *Darlington Statement* is a community consensus platform developed by Australian and New Zealand intersex organisations and advocates in 2017 (AIS

Support Group Australia et al. 2017). It covers a range of priorities in relation to protections for bodily integrity (including a call for a prohibition of deferrable medical interventions), standards of care, peer and family support, and sex markers. It issues direct calls for reforms to anti-discrimination legislation including:

*11. We call for an end to **genetic discrimination**, including in insurance and employment.*

Recommendation 5

'Genetic discrimination' be made unlawful, separate to 'irrelevant medical record' or 'impairment', with regulation to ensure that breaches can be effectively eliminated.

6 Question 36: sex characteristics

An additional attribute of sex characteristics should be introduced. Sex characteristics do not solely offer protection to people with innate variations of sex characteristics. 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.

6.1 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 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 6

In line with best practice developments in international human rights law, the *Yogyakarta Principles plus 10*, the *Darlington Statement*, and developments in ACT, Tasmania and Victoria, we recommend that Queensland reform the *Anti-Discrimination Act 1991* by prohibiting discrimination on the ground of 'sex characteristics', as follows:

***sex characteristics* means a person's physical features relating to sex, and includes:**

- (a) the person's genitalia and other sexual and reproductive parts of the person's anatomy; and**
- (b) the person's chromosomes; and**
- (c) the person's hormones; and**
- (d) secondary features emerging as a result of puberty.**

7 Questions 40, 54 and 56: sport

Intersex people suffer exclusion and stigmatisation in sport. This takes multiple forms. On a day-to-day level, the most significant issue faced by intersex people in sport settings is body shaming, and the idea that our bodies are too masculine or too feminine.

7.1 Whose bodies are problematised?

Not all people with innate variations of sex characteristics have bodies that are problematised in sport regulations.

- Intersex people who change legal sex classification may face some of the same challenges that face transgender people. Because these issues are not shared by cisgender intersex people but are shared by other people who change sex marker, this can be regarded as discrimination on grounds of gender identity, perhaps compounded by having an intersex variation. Like all people exposed to unnecessary medical interventions, this population may experience impaired sexual function and sensation. Unique and profoundly harmful issues faced by people with this experience include exposure to unnecessary medical interventions to reinforce an inappropriate sex of rearing.
- The same challenges associated with being transgender are also unfortunately likely for intersex people who have non-binary, alternative and multiple sex markers.
- There are no legal or other issues in sport by intersex men, and no justifications for their exclusion. No international sports body has ever introduced exclusions for men with innate variations of sex characteristics.
- Some – but not all – women with innate variations of sex characteristics face exclusion, such as the idea that, even observed, assigned and raised as girls, with a lifelong social and legal status as women, they should not be permitted to compete as women. This is a distinct issue from participation by transgender women, as women with intersex variations who are targeted by exclusions have never sought to transition or change sex classification; they seek to compete in their birth-observed classification.

In our view, these differences and distinctions make the application of any generalised exemption for sport in relation to sex characteristics unreasonable, unnecessary and disproportionate.

Salacious public attention on the bodies of women with intersex variations has persisted for more than a decade since an Australian newspaper first reported on leaked claims in relation to Caster Semenya in 2009. In our view, this media attention has created a climate of fear and suspicion that harms all people born with intersex variations.

7.2 World Athletics regulations

Historically, testing to ensure that women competitors are women has arisen because of a view (supported by performance data in some sports) that mixed-sex competition would adversely impact the inclusion of women in sport, and that women's sport needs to be protected from participation by men (Padawer 2016). It has arisen, then, in a climate of hostility towards perceived masculinity in women's sport, and fear of perceived deviance. These rationales persist (Karkazis and Jordan-Young 2014; Karkazis and Carpenter 2018; Human Rights Watch 2020).

Initially, sex testing of women athletes involved examinations of women's genitals and other sex characteristics. Chromosomal analysis was later introduced. Both of these were discontinued, the latter because of the impact on women with androgen insensitivity, including women who suffered profound harms as a consequence, including public humiliation (Martínez-Patiño 2005; Padawer 2016; Sengupta 2014). In many cases, being examined for competition was the first time that some women discovered their intersex trait (Martínez-Patiño 2005; Padawer 2016; Sengupta 2014). It should be noted that this situation is plausible in some situations in Queensland, where Adikari and others (2019) identify that many individuals only come to the attention of clinicians in adolescence.

Subsequent guidelines in athletics have drawn an arbitrary line between acceptable and unacceptable levels of testosterone in women athletes. Sex testing guidelines include hormone testing, chromosome and genetic testing, and genital and other physical examinations. Consequences of discovery are disturbing (Human Rights Watch 2020).

Current World Athletics regulations (International Association of Athletics Federations 2019) directly impact only a small subset of 'restricted' athletics events, where World Athletics perceives a purported advantage:

400m races, 400m hurdles races, 800m races, 1500m races, one mile races, and all other Track Events over distances between 400m and one mile (inclusive), whether run alone or as part of a relay event or a Combined Event' (International Association of Athletics Federations 2019).

These current regulations impact only a subset of women with innate variations of sex characteristics, including those with:

(A) *5 α -reductase type 2 deficiency;*

(B) *partial androgen insensitivity syndrome (PAIS);*

(C) *17 β -hydroxysteroid dehydrogenase type 3 (17 β -HSD3) deficiency;*

(D) *ovotesticular DSD; or*

(E) *any other genetic disorder involving disordered gonadal steroidogenesis; (International Association of Athletics Federations 2019).*

These traits include the trait of the child in the Family Court case *Re: Carla (Medical procedure)*, adjudicated in Brisbane in 2016. These also include the traits of individuals subjected to genital surgeries in infancy due to early identifiable genital variations, as described in the presentation on cases seen by a Brisbane paediatric and adolescent gynaecology team (Adikari et al. 2019).

Women athletes with these traits are only impacted where an athlete falls subject to the following criteria:

she has circulating testosterone levels in blood of five (5) nmol/L or above [...]

she has sufficient androgen sensitivity for those levels of testosterone to have a material androgenising effect.⁶

A deliberate impact of early surgical interventions on children and adolescents with the specified traits is sterilisation, meaning that these criteria are not met in any children subjected to such surgeries. To recap, Adikari et al (2019) state ‘Gonadectomy was performed in all cases, except in the Turner’s variant’ – meaning that all adolescents seen by the Paediatric and Adolescent Gynaecology Service in Brisbane with traits subject to World Athletics regulations have experienced sterilisation. While our desire for individuals to have autonomy over their own bodies means that we would wish it otherwise, it is likely that, at present, no girls or women with innate variations of sex characteristics treated in Brisbane are impacted by both of these World Athletics criteria.

These surgeries to make children’s bodies fit gender stereotypes associated with sex of rearing are mirrored in surgical interventions on women athletes. In 2013, it was reported that several women athletes had been subjected to gonadectomies (i.e. sterilisation) and clitoral reduction surgeries as part of a process intended to facilitate their participation in competitive sport (Fénichel et al. 2013). This has been condemned by other clinicians and bioethicists (Ha et al. 2014; Jordan-Young, Sonksen, and Karkazis 2014), as well as intersexed organisations and the United Nations.

Do later regulations requiring hormonal treatment in women with higher testosterone levels ameliorate requirements for ‘treatment’? In our view, it is the demand for treatment in return for acceptance that is the problem, not the type of treatment required.

In an invited commentary in the *Journal of Medical Ethics*, Morgan Carpenter discusses the impact of a legal decision by the Court of Arbitration for Sport (CAS) upholding World Athletics regulations. He states that such regulations contribute to a coercive social environment:

While a majority decision by CAS adjudicators denied consideration of the ‘wider impact’ of their decision outside sport, it has consequences – outside sport and in hospitals – for everyone with an intersex trait. It sends a message that the world is inhospitable, that people with intersex variations don’t belong, unless our bodies are changed to fit in (Carpenter 2020).

The relationship between such regulations and coercive medical interventions raises moral questions about their imposition or facilitation in law. Human rights institutions have raised significant and persuasive objections to such regulations, calling for their termination (United Nations Human Rights Council 2019; Office of the High Commissioner for Human Rights 2019; UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health 2016). In 2021, the International Olympic Committee issued revised regulations due in part to these concerns (International Olympic Committee 2021).

Only 'sparse' evidence exists relating to the sporting performance of women with intersex variations, with concerns about the integrity of this evidence leading to the review of a key peer-reviewed journal article (Handelsman, Hirschberg, and Bermon 2018; Pielke, Tucker, and Boye 2019). Key evidence supporting testing was 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' (Longman 2021; BMJ Publishing Group Ltd and British Association of Sport and Exercise Medicine 2021). This situation does not support generalised exemptions on grounds of sex characteristics.

World Athletics regulations are also contested on the basis that they are grounded in racialised conceptions of beauty and body norms, and disproportionately impact women from low income and resource poor countries and regions (Karkazis and Jordan-Young 2018).

World Athletics regulations associate the existence of new sex classifications with intersex people, and suggested that women with intersex variations who refuse the medicalisation of their bodies be consigned to those classifications irrespective of their legal status; this appeared to be designed to humiliate (Karkazis and Carpenter 2018; Human Rights Watch 2020):

with the passage of time and the recurring public spectacle of young women, often from less-developed areas of the world, having their underlying biology indiscriminately scrutinized in the world media, it has become evident that the hyperandrogenism policies are no more salutary than earlier attempts to define sharp sex boundaries (Genel M, Simpson J, and de la Chapelle A 2016)

7.3 Australian human rights guidelines and legislation

While attempts have been made to survey the experience of intersex people in sport, as part of studies on LGBTI people (ACT Human Rights Commission et al. 2014) or transgender and intersex people (Australian Human Rights Commission 2015; ACT Human Rights Commission 2017), their framing has failed to be relevant or sensitive to the needs of people with intersex variations, and low sample sizes mean that the data are not representative.

Anecdotally, and in research on educational needs (Jones 2016), we are aware of multiple people who avoid participation in sport because of experiences of body shaming and

developmental delays. We also know individuals treated on the advice of Australian doctors who have been advised they should not compete in sport, despite a history of medical interventions and lack of intention to compete.

Under some circumstances, federal legislation permits that exclusion. For example, the *Sex Discrimination Act 2013* (Cth) section 42 permits exclusions for participants in 'any competitive sporting activity in which the strength, stamina or physique of competitors is relevant' in persons aged 12 or over. IHRA opposed this inclusion when it was introduced into legislation in 2013 (Carpenter and Organisation Intersex International Australia 2013). In response to questions by an inquiry of the Senate Standing Committee on Legal and Constitutional Affairs, the Attorney General's Department stated:

The Department understands the operation of the exemption in State and Territory law will often involve a case-by-case assessment of individual circumstances. That is, the exemption is not intended to operate to require sporting competitions to have policies which automatically exclude people who are intersex, or people with a gender identity which does not match their birth sex. Instead, it is to provide reassurance that organisers are able to make decisions to guarantee fair competition in sporting events. (Attorney General's Department 2013)

It is our view that, far from limiting cases, suggestions that case-by-case assessment are likely to raise unnecessary questions for individuals where assessment is unnecessary, unreasonable and disproportionate, including men, and including cisgender women competing in unrestricted events.

Further, it is our view that clear reproducible and replicable evidence of any purported performance advantage is essential for any party seeking to exclude a woman with an innate variation of sex characteristics from competitive sport. No such evidence exists and the human rights position is unequivocal.

The Equal Opportunity Act 2010 (Vic) was updated in 2021 to provide protections on grounds of sex characteristics. No sports exemption applies on this ground. Language in the Act referring to exclusion of people of one sex from competition does not appear to us to impact on cisgender women and men with innate variations of sex characteristics.

The Discrimination Act 1991 (ACT) similarly contains no exemption on grounds of sex characteristics. Language in the Act on excluding people of one sex from participation appears to us unlikely to impact on cisgender women and men with innate variations of sex characteristics.

7.4 Our position and recommendations

Our position is set out in the 2017 *Darlington Statement*, an Australian – Aotearoa/New Zealand intersex community declaration, which remarks:

35. We call for **access to sport** at all levels of competition by all intersex persons, including for all intersex women to be permitted to compete as women, without restrictions or discriminatory medical investigations.

In line with the *Yogyakarta Principles plus 10*, we support the following State Obligations on the rights to equality and non-discrimination:

I) *Ensure that all individuals can participate in sport in line with the gender with which they identify, subject only to reasonable, proportionate and non-arbitrary requirements;*

J) *Ensure that all individuals can participate in sport without discrimination on the grounds of sexual orientation, gender identity, gender expression or sex characteristics;*

K) *Adopt legislative, policy and other measures in line with international human rights norms and standards to eliminate bullying and discriminatory behaviour at all levels of sports, on the basis of sexual orientation, gender identity, gender expression and sex characteristics; (Yogyakarta Principles 2017)*

Our recommendations are also in line with our understandings of the legal situation in ACT and Victoria.

Recommendation 7

No sports exemptions should apply on grounds of sex characteristics.

Recommendation 8

Regulations and guidance on including people with innate variations of sex characteristics in sport should always state that women and men with innate variations of sex characteristics can play or compete in their birth-observed/birth-assigned sex.

Recommendation 9

Regulations and guidance affecting people who have changed sex marker should always be reasonable, proportionate, and impose only the minimum necessary regulation.

8 Questions 41, 42, 43 and 44: religious exemptions

The 2013 amendment to the *Sex Discrimination Act 1984 (Cth)* enacted exemptions permitting discrimination by religious schools on grounds of sexual orientation and gender identity, but not intersex status (Commonwealth of Australia 2013). The explanatory memorandum for the then bill notes:

The Bill will not extend the exemption to cover the new ground of intersex status. During consultation, religious bodies raised doctrinal concerns about the grounds of sexual orientation and gender identity. However, no such concerns were raised in relation to 'intersex status'. As a physical characteristic, intersex status is seen as conceptually different. No religious organisation identified how intersex status could cause injury to the religious susceptibilities of its adherents. Consequently, prohibiting discrimination on the basis of intersex status will not limit the right to freedom of thought, conscience and religion or belief. (House of Representatives 2013)

Unfortunately, media reporting frequently fails to accurately describe current legislation, with consequences for public understanding. Nevertheless, the intent of current Commonwealth laws is not to permit discrimination against intersex people because of intersex variations on religious grounds.

8.1 The religious freedoms review (2018)

The Religious Freedoms review (also known as the Ruddock review) positioned intersex alongside race, disability, and pregnancy, and not with sexual orientation and gender identity:

Recommendation 1

Those jurisdictions that retain exceptions or exemptions in their anti-discrimination laws for religious bodies with respect to race, disability, pregnancy or intersex status should review them, having regard to community expectations. [...]

Recommendation 6

Jurisdictions should abolish any exceptions to anti-discrimination laws that provide for discrimination by religious schools in employment on the basis of race, disability, pregnancy or intersex status. Further, jurisdictions should ensure that any exceptions for religious schools do not permit discrimination against an existing employee solely on the basis that the employee has entered into a marriage. [...]

Recommendation 8

Jurisdictions should abolish any exceptions to anti-discrimination laws that provide for discrimination by religious schools with respect to students on the basis of race, disability, pregnancy or intersex status. [...]

1.141 While the Panel accepted that some variation in approaches between jurisdictions was appropriate to reflect the values of different communities, it could see no justification for exceptions in existing law relating to race, disability, pregnancy or intersex status. The Panel is of the view that those jurisdictions retaining exceptions should review them having regard to community expectations. (Ruddock et al. 2018)

Little justification was presented in support of this positioning of intersex status, however, the reasoning can be discerned from the presentation of historical information on religious attitudes towards intersex people, and the following statements by Patrick Parkinson, author of the submission to the religious freedoms inquiry by Freedom for Faith:

The rights and needs of those with intersex conditions do not conflict with religious values. (Freedom for Faith 2018, footnote 15, page 25)

8.2 Implications of ‘sex characteristics’

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

8.3 Our position and recommendation

The *Darlington Statement* comments:

*42. We recognise the needs and lived experience of **youth**, and of people coming from varied **cultural and faith backgrounds**. We recognise these experiences as valid and legitimate (AIS Support Group Australia et al. 2017).*

In our view, despite this broad reach, there are no implications for religious exemptions that are not already identified for intersex status.

Recommendation 10

In line with developments in ACT and Victoria, and the report of the religious freedoms review panel, no religious exemptions should be enacted on grounds of sex characteristics.

9 Questions 45 and 56: working with children exemption

The discussion paper asserts that:

A work exemption unique to Queensland permits people who are sex workers (lawful sexual activity attribute), or who are transgender or intersex (gender identity attribute) to be discriminated against in relation to employment that involves the care or instruction of minors. The exemption applies where it is 'reasonably necessary to protect the physical, psychological or emotional wellbeing of minors having regard to all the relevant circumstances of the case, including the person's actions'. (Queensland Human Rights Commission 2021, 118)

This is a shocking, stigmatising and offensive assertion and exemption. As stated earlier in our submission in relation to the gender identity attribute, the purported inclusion of discrimination against intersex people within the attribute of gender identity was opposed at the time, and is inappropriate and misleading. To then apply an exemption that supposes that someone with a genetic or otherwise innate trait should be subject to an exclusion in relation to working with children is profoundly wrong, offensive and stigmatising.

We fear that the Commission's presumption here that the gender identity attribute validly refers to people who are intersex is unwise and puts intersex people in a harmful position. It gives us grave cause for concern in relation to the likely submissions to this public inquiry that will eventuate as a consequence.

9.1 Our position and recommendation

In our view, this exemption is unreasonable, unnecessary and disproportionate.

Recommendation 11

The working with children exemption should be repealed, and a formal apology should be made to individuals who have experienced exclusion and stigmatisation because of its existence.

10 Question 46: assisted reproductive technologies

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, 5 α -reductase deficiency (5 α -RD2) and 17 β -hydroxysteroid dehydrogenase 3 deficiency (17 β -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. 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). Low rates of diagnosis may be linked to varying expression of the trait. 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).

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 a 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).

10.1 Our position and recommendation

In line with the *Darlington Statement* and the *Yogyakarta Principles plus 10*, we call for an end to discrimination in the 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 12

Both applications of, and access to, assisted reproductive technologies must not discriminate on the basis of sex characteristics.

At the very least, ‘non-syndromic’ 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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