



February 2022

**Preliminary Submission on reform of the *Anti-Discrimination Act 1977 (NSW)***

**Intersex Human Rights Australia (IHRA)**



# 1 Introduction

Thank you for inviting preliminary submissions on reform of the *Anti-Discrimination Act 1977 (NSW)*. Intersex Human Rights Australia (IHRA) welcomes the opportunity to make such a submission.

The focus of this submission is to identify an appropriate ground for protection (“sex characteristics”), and provide a briefing on some of the more common innate variations of sex characteristics.

In this submission we do not consider other matters, such as the tests for discrimination. We recognise the importance of ensuring that comparator tests do disadvantage stigmatised minority populations like ours, and we support the work of the Public Interest Advocacy Centre (PIAC) in its 2021 report “Leader to Laggard” (Public Interest Advocacy Centre 2021).

We also wish to place on record our preference for the enactment of a Human Rights Act in New South Wales.

## 1.1 About this submission

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

## **1.2 Authorship**

This submission by IHRA has been written by Morgan Carpenter, M.Bioeth (Sydney), M.InfTech (UTS), executive director of IHRA.

Morgan Carpenter is a bioethicist and intersex human rights defender, with lived experience. He is a research affiliate in the University of Sydney School of Public Health, and a cofounder and executive director of Intersex Human Rights Australia. In 2023, Morgan's "tireless work" was recognised by the Australian Capital Territory's Chief Minister when introducing Australian-first legislation to protect the rights of people with innate variations of sex characteristics in medical settings ('Daily Hansard: Transcript 22 March 2023' 2023). He has been named as a significant contributor to a 2021 Australian Human Rights Commission report on the health and human rights of people born with variations in characteristics (Australian Human Rights Commission 2021). He was an expert and drafting committee member for the *Yogyakarta Principles plus 10* (Yogyakarta Principles 2017). In 2013 he designed and shared the intersex flag, framed around concepts of bodily integrity and autonomy (Carpenter 2013). He works nationally and internationally, including participation in the first expert meeting held by the UN on ending human rights violations against intersex persons (Office of the High Commissioner for Human Rights 2019). Morgan has been contracted to the Office of the High Commissioner for Human Rights, the Australian Capital Territory government and the Australian Institute of Health and Welfare. He is a reference or advisory group member for the Australian government's Department of Health and Aged Care, the Australian Bureau of Statistics, and New South Wales Health.

## **1.3 Contact details**

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### 3 Sex and sex characteristics

The term “sex” has multiple different meanings. While those different meanings often have little impact on people who do not have intersex variations, they can have significant consequences for people with innate variations, and those consequences can vary according to the definition.

Sex can refer to **biological characteristics**, particularly in approaches that seek to distinguish sex from gender. Such models are used in particular to highlight social and cultural norms attributed to people with different biological characteristics (and resulting disadvantage experienced by women), and to explain the existence of transgender people (as people whose gender does not match their sex at birth). In our view, using the term sex to refer to biological sex/biological sex characteristics conflates numerous characteristics and processes. It presumes that there are two (in some cases three) types of biological characteristics that have a neat and clearly defined relationship to a legal and social status.

Sex can also refer to a **legal status**, initially determined on the basis of sex characteristics observed or assigned at birth. This meaning of the term sex is sometimes referred to as ‘sex at birth’, and is reflected in national statistical standards such as the Australian Bureau of Statistics Standard on Sex, Gender, Variations of Sex Characteristics, and Sexual Orientation (Australian Bureau of Statistics 2021). It is also reflected in a real world process that happens in hospitals. For example, the Standard identifies a relationship between sex and sex characteristics, such that the former is determined by observation of the latter:

*Sex is understood in relation to sex characteristics. Sex recorded at birth refers to what was determined by sex characteristics observed at birth or infancy (Australian Bureau of Statistics 2021).*

The Standard also notes that attempting to count intersex people within a question on sex does not produce useful results, because people with innate variations of sex characteristics are not actually assigned or observed as belonging to a distinct sex. While intersex is currently an option for birth registrations in the ACT and SA, this is not supported by community, and this legal category in the ACT is under review as no children with intersex variations have been assigned to it in the 9 years since it was created.

The Standard states:

*While intersex is an option available in some Australian jurisdictions and elsewhere for birth certificates, and may be captured in the 'Another term' response option, this should not be used as a count of people who have variations of sex characteristics. Many variations of sex characteristics are not evident at birth, and people may not be aware they were born with a variation of sex characteristics until puberty or later in life. The inclusion of born with a variation of sex characteristics or intersex as a response option in a sex question, alongside male and female, is not capable of generating reliable or consistent results in measuring this population, and perpetuates the misconception that intersex people are neither male nor female (Australian Bureau of Statistics 2021).*

A community consensus statement, the Darlington Statement, says:

*attempts to classify intersex people as a third sex/gender do not respect our diversity or right to self determination. These can inflict wide-ranging harm regardless of whether an intersex person identifies with binary legal sex assigned at birth or not (AIS Support Group Australia et al. 2017)*

While online debate often presumes that a single variable is responsible for sex (such as gametes produced, chromosomes, gametes that might be produced in different material realities), the observed/assigned sexes of people with innate variations of sex characteristics follow a set of rules which can vary from hospital to hospital. These rules are not random, but they are to some extent subjective. For example, a current textbook for endocrinologists states:

*Factors that influence sex assignment include the diagnosis, genital appearance, surgical options, need for lifelong replacement therapy, the potential for fertility, views of the family and sometimes, circumstances relating to cultural practices (Ahmed and Ali 2022, 31).*

NSW paediatric endocrinologists wrote in an Australian clinical journal in 2020:

*assignment is a dilemma in a small percentage of patients with DSD and requires an individualised approach taking into consideration prenatal androgen exposure, fertility potential, quality of sexual function, surgical options, gonadal pathology/malignancy risk and potential adult gender identity (Vora and Srinivasan 2020, 418).*

Cultural practices, genital appearance, “surgical options”, view of the family, “quality of sexyual function” are all subjective assessments relating to individuals, their families and surgeon’s skills and preferences for feminising or masculinising surgeries in each case. Assessment of potential adult gender identity is made on an empirical basis, using specific data on the identities of adults with each diagnosis. This empirical data is reflective of a situation where clinicians seek to construct cisgender adults – people who identify with sex assigned at birth. Indeed, while more people with intersex variations are likely to change sex assignment, or experience gender dysphoria, than non-intersex people, most people with intersex variations are cisgender, that is, we identify with sex assigned at birth (Furtado et al. 2012).

These data are subject to confirmation and ascertainment biases, but this is not so troubling as the reference to “surgical options”, which refers to a set of medical interventions aimed at ensuring “social and familial integration” and conformity with gendered and sexed expectations for girls and boys.

In 2017, the Darlington Statement called for criminalisation of such “deferrable” medical interventions on people without age or agency to personally consent (AIS Support Group Australia et al. 2017).

In 2021, the Australian Human Rights Commission called for the criminalisation of surgical and other treatments grounded in gender stereotypes, and social and familial integration (Australian Human Rights Commission 2021).

In 2023, the Australian Capital Territory has become the first jurisdiction to introduce and pass legislation to give effect to this demand (Chief Minister, Treasury and Economic Development Directorate 2023).

**The implications of this for the Law Reform Commission are that intersex variations are not a sex, and are not protected in anti-discrimination legislation by references to sex.**

### **3.1 Anti-Discrimination Act 1977 (NSW)**

The Anti-Discrimination Act 1977 (NSW) refers to people of “indeterminate sex” within the definition of “transgender person”:

*(a) who identifies as a member of the opposite sex by living, or seeking to live, as a member of the opposite sex, or*

*(b) who has identified as a member of the opposite sex by living as a member of the opposite sex, or*

*(c) who, being of indeterminate sex, identifies as a member of a particular sex by living as a member of that sex, (New South Wales 1977).*

Given that people with intersex variations are assigned to, or observed, a female or male sex, we have never understood how this can be interpreted in a way that usefully protects people with intersex variations. Who is of indeterminate sex? What does this protection mean, for example, for girls and women with intersex variations who are assigned female at birth, and who understand themselves as women? Are they of indeterminate sex? If so, where and when did they become of indeterminate sex? How are they different in law from girls and women who don't have intersex variations?

The definition of what it means to be transgender explicitly proposes a distinction between birth sex assignment and gender identity that does not apply to most intersex people, because most people with intersex variations never change sex category. Additionally the NSW legislation offers greater protection to “recognised transgender persons” who have recorded an alteration of sex.

While people perceived of being transgender are protected, the framing of the legislation makes the protections unavailable and difficult to understand. We note that the Anti-Discrimination Board of NSW makes no assertion that intersex people are protected in the Act (Anti-Discrimination Board of New South Wales and NSW Department of Justice 2021).

## 3.2 Sex characteristics

**Most States and Territories have introduced protections from discrimination on grounds of “sex characteristics”. These include:**

- Protections on grounds of “sex characteristics” introduced in the Justice Legislation Amendment Act 2020 (ACT) (Australian Capital Territory 2020).
- Inclusion of “sex characteristics” in the Anti-Discrimination Act 1992 (NT) a result of the Anti-Discrimination Amendment Bill 2022 (NT) (Paech 2022).
- An update to the Anti-Discrimination Act 1991 (Qld) that passed in 2023 (Queensland Parliament 2022).
- Reforms in Tasmania in 2019 that added “intersex variations of sex characteristics”, which we identify as not best practice (see Tasmanian Legislation Online 2019).
- Reforms in Victoria to the Equal Opportunity Act in 2021 (see Victoria 2010).
- The Law Reform Commission of Western Australia has recommended introduction of protections on grounds of sex characteristics” in that jurisdiction (Law Reform Commission of Western Australia 2022).

None of these jurisdictions have introduced exemptions on grounds of sex characteristics.

The enactment of protection with this attribute has not by itself been controversial in any jurisdiction. (Anti-discrimination legislation has been amended in some cases through legislation to prohibit LGBT conversion practices and modify birth registration processes, which have provoked debate, but the attribute of sex characteristics was not a feature of debate in these broader reforms.)

**The federal government has also committed to introducing protections on the same ground of “sex characteristics”.**

A public commitment to this reform was made during debate in the House of Representatives on the Fair Work Legislation Amendment (Secure Jobs, Better Pay) Bill on 10 November 2022. The commitment was made by Minister Tony Burke. Minister Burke wrote to us in December 2022 confirming this commitment, and a copy is appended to this preliminary submission.

The attribute of “sex characteristics” is intended to offer universal protections, without any associations with legal status, identity, or behaviour.

**Legislation in Queensland represents the latest and clearest articulation of the attribute “sex characteristics”:**

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



*(a) genitalia, gonads and other sexual and reproductive parts of the person's anatomy;  
and*

*(b) the person's chromosomes, genes and hormones that are related to the person's  
sex; and*

*(c) the person's secondary physical emerging as a result of puberty (Queensland  
Parliament 2022)*

**We recommend that the New South Wales government introduce protections on grounds of "sex characteristics".**

Doing so will implement useful, meaningful protections for people with innate variations of sex characteristics, and align protections in New South Wales with protections in most other Australian jurisdictions.

**We also encourage harmonisation of protections against vilification and sexual harassment, and positive obligations, such that they also offer protections and obligations on grounds of sex characteristics.**

## 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 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.

### 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 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 NSW 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).

## 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 has been introduced 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 (Safer Care Victoria 2021)*

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).*

#### **4.3 17-beta hydroxysteroid dehydrogenase 3**

Infants with 17-beta hydroxysteroid dehydrogenase 3 (17 $\beta$ -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 2018; World Health Organization 2022).*

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 $\beta$ -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 2022), 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 $\beta$ -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 $\beta$ -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.

#### **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 (Skakkebak, 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 (Skakkebak, 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.

#### **4.5 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)*

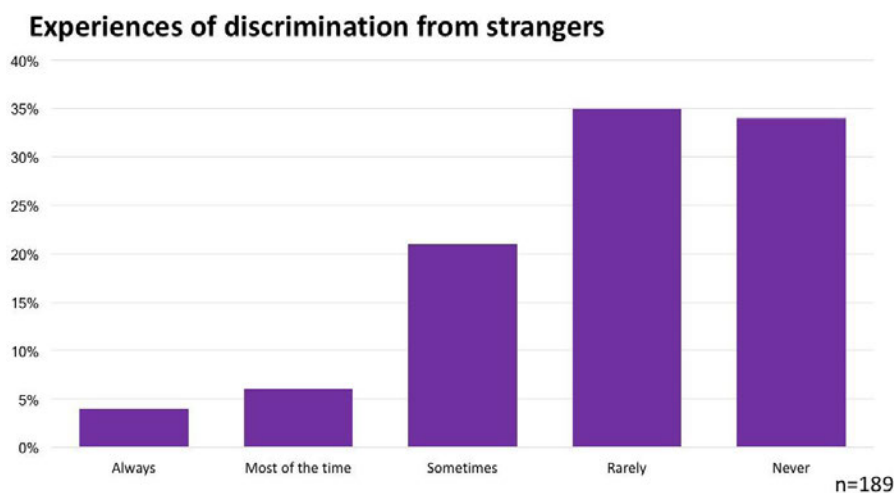
This lies behind our rejection in the *Darlington Statement* of associations between intersex variations and exclusion from, or inclusion in, any category of sex as a population (AIS Support Group Australia et al. 2017). We support choice at an individual level where this does not impact the rights of 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.<sup>1</sup>



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.

## 5 Issues not addressed in this submission

In this submission we do not consider other matters, such as the tests for discrimination. We recognise the importance of ensuring that comparator tests do not disadvantage stigmatised minority populations like ours, and we support the work of the Public Interest Advocacy Centre (PIAC) in its 2021 report “Leader to Laggard” (Public Interest Advocacy Centre 2021).

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

## **6 Letter from Minister Burke**

A public commitment to this reform was made during debate in the House of Representatives on the Fair Work Legislation Amendment (Secure Jobs, Better Pay) Bill on 10 November 2022. The commitment was made by Minister Tony Burke. Minister Burke wrote to us in December 2022 confirming this commitment, and a copy follows overleaf.



**The Hon Tony Burke MP**  
**Minister for Employment and Workplace Relations**  
**Minister for the Arts**  
**Leader of the House**

Morgan Carpenter  
Executive Director  
Intersex Human Rights Australia  
PO Box 51  
ALTONA VIC 3018

Dear Mr Carpenter

Thank you for your letter of 4 November 2022 calling for reforms to the *Fair Work Act 2009* to end the omission of protections for people with innate variations of sex characteristics.

I am pleased to advise that on 6 December 2022, the *Fair Work Legislation Amendment (Secure Jobs, Better Pay) Act 2022* received Royal Assent. The Act strengthens the anti-discrimination protections in the Fair Work Act by adding 'intersex status', 'gender identity' and 'breastfeeding' to the list of protected attributes in various parts of the Act, including in relation to adverse action and unlawful termination. It also amends the Fair Work Act to confirm that 'special measures to achieve equality' are permitted matters which can be dealt with in enterprise agreements--enabling parties to bargain for terms in enterprise agreements which have the purpose of achieving equality for employees with protected attributes.

I note your indication that it is now international best practice, as set out in IHRA's *Call for action on intersex health and human rights*, to provide protection on the ground of 'sex characteristics' in place of 'intersex status'. The reforms to the Fair Work Act have initially retained the term 'intersex status' to ensure compatibility and consistency with relevant provisions of other Commonwealth anti-discrimination legislation.

During the debate on the Secure Jobs Bill, I placed on the record the Government's intention to progress further action to address this matter, and ensure best practice, across all relevant anti-discrimination legislation. I enclose for your reference a copy of the Hansard extract.

I have copied this letter to the Hon Mark Dreyfus KC MP, the Attorney-General. I trust this information is of assistance.

Yours sincerely

**THE HON TONY BURKE MP**

d'-IJJ 2022

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