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Submission on the Education Legislation Amendment (Parental Rights) Bill 2020

Intersex Human Rights Australia (IHRA)



1 Contents

1	Contents	2
2	About this submission	3
3	Recommendation	4
4	Context	4
5	Specific areas of concern with the bill	5
5.1	Inappropriate use of pathologising language	6
5.2	Failure to meet legal non-discrimination obligations	6
5.3	Disruption to education	6
6	The needs of intersex people in education in NSW	7
7	The needs of intersex people in NSW anti-discrimination law	9
8	Appendices	10
8.1	Appendix A: Who are intersex people	10
8.1.1	Some examples of intersex variations	11
8.1.1.1	Klinefelter syndrome/47,XXY	12
8.1.1.2	Androgen insensitivity	12
8.1.1.3	Congenital adrenal hyperplasia	13
8.1.1.4	17-beta hydroxysteroid dehydrogenase 3	15
8.2	Appendix B: Community priorities	17
8.2.1	Bodily integrity	17
8.2.1.1	Bodily integrity and international law	18
8.2.1.2	Bodily integrity in Australia	20
8.2.2	Anti-discrimination law	20
8.2.3	Sex markers	21
8.2.4	Education	23
9	References	25

2 About this submission

This Report is submitted by [Intersex Human Rights Australia](#) ('IHRA'), a national charitable organisation run by and for people born with intersex variations, formerly known as Organisation Intersex International (OII) Australia. We promote the health and human rights of people born with intersex variations, 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 co-executive directors and other 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).

Since December 2016 we have been funded by foreign philanthropy to employ two part-time co-executive directors to engage in policy development and systemic advocacy work. Our resourcing is inadequate to meet the demands we face.

The submission was written by co-executive director Morgan Carpenter, M.Bioeth. (Sydney) and Dr Agli Zavros-Orr. Morgan Carpenter is a Justice of the Peace in New South Wales (number 223963) and is mid-way through a PhD in bioethics in the School for Public Health, University of Sydney. Dr Agli Zavros-Orr has worked as an early childhood and primary teacher and is a teacher educator. Her doctoral studies focused on the ethics of care, school leadership, teacher's work and supportive school environments.

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3 Recommendation

Intersex Human Rights Australia is unable to support this bill. We recommend that it does not proceed. The bill is discriminatory. The bill and second reading speech frame people born with intersex variations in contradictory, marginalising and inappropriate ways. They undermine the right of every student to a quality education in a supportive environment.

4 Context

Intersex people have innate sex characteristics that don't fit medical and social norms for female or male bodies, and that create risks or experiences of stigma, discrimination and harm. Intersex variations are heterogeneous, and a natural part of human biological diversity.

Intersex traits include androgen insensitivity syndrome, congenital adrenal hyperplasia with X sex chromosomes, 'hyperandrogenism', micropenis, 17-beta hydroxysteroid dehydrogenase 3 deficiency syndrome, and gonadal dysgenesis (Intersex Human Rights Australia 2016).

Current medical and legal approaches towards intersex people are disjointed and impose contradictory demands. That is, medicine constructs intersex bodies as either female or male and in need of medical intervention, while law and increasingly society construct intersex identities as neither female nor male (Carpenter 2018b, 2018c). The effects of current clinical and legal frameworks are that intersex bodies remain surgically and hormonally 'normalised' by medicine. Current medical practices in Australia violate human rights through forced and coercive medical interventions (Human Rights Committee 2017; Committee on the Elimination of Discrimination against Women 2018; Committee on the Rights of Persons with Disabilities 2019; Committee on the Rights of the Child 2019).

At the same time, society and the law 'other' intersex identities. Misconceptions about intersex people frequently associate particular gender identities or sex classifications with intersex traits - for example, an incorrect assumption that intersex people have non-binary gender identities. In reality, the intersex population is diverse, and individuals often grow up to identify with sex assigned at birth, while some do not, and individuals with intersex traits often grow up to identify as heterosexual, while many do not.

Intersex people use a wide variety of terms to describe ourselves, typically reflecting words we are taught by our parents and doctors, and in response to misconceptions and stigma. Those words can include diagnosis-specific terms, intersex, intersex variations or conditions, innate variations of sex characteristics, or differences of sex development. Individuals whose intersex variation is more evident to strangers are more likely to bear the brunt of social discrimination (Jones 2017).

In this context, where different social and political groups create radically different understandings of who intersex people are and how we should be treated, we note with

great concern proposals put to the Legislative Council by Mark Latham MLC. The *Education Legislation Amendment (Parental Rights) Bill 2020* appears primarily directed at prevention of discussion of the existence of transgender people, but it also has an impact on people with intersex variations.

We expect that many commenters, even those who profess to represent 'LGBTI' communities, will be unaware of this impact because of the prevalence of misconceptions.

5 Specific areas of concern with the bill

The *Education Legislation Amendment (Parental Rights) Bill 2020* bill and the second reading speech by Mr Latham present three radically different ideas of who intersex people are:

- the bill refers to 'people who are, by their chromosomes, male or female but are born with disorders of sexual differentiation', within a statement on 'gender fluidity' and a definition of biological sex (Latham 2020a). This reference makes the claim that intersex people are female or male but have certain disorders.
- the second reading speech by Mark Latham contrarily refers at 16:50:42 on 5 August to 'the fixed biological reality of gender in that, other than a small number of cases, people are born male or female' (Latham 2020b). This reference makes the claim that intersex people are not female or male and perhaps have no 'fixed biological reality of gender', suggestive of gender fluidity.
- the second reading speech also refers to a 'MultiVerse' module on 'Intersex Identities' (Latham 2020b). This reference is suggestive that intersex is an identity category. This module has been misinterpreted. It was an interview delivered by Dr Agli Zavros-Orr, the chair of IHRA and a Cypriot-Australian talking about her personal experience of an intersex variation and with a PhD in early education. The module aims to promote awareness of the impacts of cultural and medical experiences and an understanding of diversity in how people with intersex variations come to understand themselves.

The existence of these contradictory ideas of who intersex people are supposed to be reflects a range of misconceptions and ideas prevalent in society more generally. These are ideas that we sadly lack the resources to effectively counter.

In the use of these contradictions and misrepresentations by the same proponent of a single bill, we see no attempt to understand who intersex people are, or address our lived experiences and the human rights violations we face. In calling for a prohibition on discussion and recognition in education of the diversity of lived human experience, the proposed bill would make it harder to educate people of our existence and realities, including our diversity as a population.

We do not support this bill, and we recommend that it does not proceed.

5.1 Inappropriate use of pathologising language

Children born with intersex variations deserve to feel safe and respected at school, in line with Australia's principles for a non-discriminatory, inclusive and values-based education. They deserve to learn affirmative information about their bodies as a natural part of human diversity. This bill promotes ignorance, non-inclusion and pathologising language.

As noted by a 2013 cross-party Senate committee inquiry on the involuntary or coerced sterilisation of intersex people, clinical language of 'disorders of sex development' inherently pathologises intersex characteristics as needing to be 'fixed' through medical intervention (Senate of Australia Community Affairs References Committee 2013); its report recommended that 'disorders of sex development' should not be used by governments and other organisations. The cross-party committee called for medical treatment of intersex people to take place within a human rights framework. We raised the recommendations of this committee report with Ministers Skinner and Goward in the O'Farrell government on release of the report in October 2013, and in subsequent fora. The NSW government has failed to act on these concerns.

The use of pathologising language is directly linked to forced and coercive medical practices. In the years since publication of that report, the Family Court has described 'feminising' surgeries on a young child as surgery that 'enhanced the appearance of her female genitalia' (Office of the High Commissioner for Human Rights 2019; Carpenter 2018a). Such actions are the consequences of a disordering of intersex variations (Dreger 2018). Silence and misconceptions – through, for example, a focus on a culture war associated with matters of personal identification, gender fluidity and respect for difference – help to perpetuate these practices.

In consideration of the needs of people with intersex variations in education, we strongly recommend to the Committee that it use the terms 'intersex variations' or 'innate variations of sex characteristics' in relation to people with intersex variations.

5.2 Failure to meet legal non-discrimination obligations

The bill appears likely to contradict non-discrimination obligations arising from the *Sex Discrimination Act 1984 (Cth)* and the flawed *Anti-Discrimination Act 1977 (NSW)*, and also the Australian Curriculum in relation to Health and Physical Education (Carpenter and Zavros-Orr 2019).

5.3 Disruption to education

The proposals to allow parental rights to withdraw children from classes that conflict with their values have the potential to disrupt learning not only on history, the European settlement of Australia, and women's right to the vote, but also the existence of the holocaust, creationism and vaccinations.

The preamble to the Melbourne Declaration by Australian Education Ministers states:

Schools play a vital role in promoting the intellectual, physical, social, emotional, moral, spiritual and aesthetic development and wellbeing of young Australians, and in ensuring the nation's ongoing economic prosperity and social cohesion. (Australian Education Ministers 2008)

The Bill disrupts cohesive relations between schools and families in their shared responsibility, care and education of the child.

6 The needs of intersex people in education in NSW

We note that, in correspondence with the NSW government regarding the bill during 2020, we wrote regarding the circumstances of people with intersex variations, naming people with congenital adrenal hyperplasia, sex chromosome variations and micropenis. In response, we received a letter from the A/Deputy Secretary in Learning Improvement in relation to students who are same-sex attracted or who have identified as transgender (Simmons 2020). While some children with intersex variations may grow up to be same-sex attracted or transgender, this is not inherent to having an intersex variation.

This lack of attention to the specific circumstances of intersex people is sadly indicative of a lack of awareness of the existence and needs of children with intersex variations in the NSW government.

Australian research based on a 2015 sociological survey shows that children and youth with intersex variations suffer from a lack of inclusive education, and risks associated with stigma, bullying and medical interventions causing absence. 18% of respondents failed to complete secondary school, compared to 2% of the Australian population (Jones 2016).

Children who are born with a variation in sex characteristics need access to quality, inclusive and socially just education and educational experiences from birth to age 18 (Carpenter and Zavros-Orr 2019; Zavros-Orr 2020; Brömdal et al. 2020). With the aim of 'doing no harm' and mindful of their circumstances, they need the following from education:

- Sufficient forethought for their physical, cognitive and psychosocial development – inclusion in educational curricula and services that is responsive to their expressed physical, social, emotional and academic needs.
- To be seen and valued – in adherence to principles of inclusion and anti-discrimination – reflective of the Convention on the Rights of the Child, as well as legislation protecting them and their rights.
- For education to be clear that intersex is not an identity and that people born with intersex variations, like their non-intersex ('endosex') peers, have a right to determine their own gender, sexuality or sexual orientation.

- For education to be inclusive of content about intersex – in a way that is not pathologising, stigmatising or discriminating. To understand that intersex people exist and are a natural part of human diversity.
- Access to content that is specifically about intersex and separate from LGBTQA+ content
- Provision of information that helps them to make sense of their bodies, especially during puberty (given diverse bodily experiences of menstruation, body shape and weight, bodily hair etc.), as well as age-appropriate sex and relationship education that is reflective of their developmental needs.
- Provision of information that helps youth with intersex variations understand that they are able to have a say about how their bodies are treated, that they can ask about ways in which they have been treated, and that they can ask to be put in touch with other people with similar experiences.
- Access to reliable age-appropriate information, role models, for the development of positive self-image, self-esteem and self-worth - that supports their sense of being, belonging and becoming as a valued member of their early learning centre, kindergarten, preschool, primary school, high school, family, community, and society in general.
- Access to funded learning and emotional support across their years of education. For example, some children have genetic intersex variations that are also associated with learning differences. Some children may need support to catch up learning from when they have been away from school due to operations or other treatment. Some children may need access to psychological or counselling resources due to trauma caused by early treatment without their informed consent and other issues related to being a person with an intersex variation (such as issues faced at home or within their cultural or faith community).
- Access to safe schooling free of bullying, discrimination or sexual abuse - related to how their physical development is influenced by their intersex variation. For example, being a teenage girl and looking boyish or being a boy and developing breast tissue.
- That children with an intersex variation are given advance notice of when potentially triggering topics are being covered in the curriculum (sex education being one obvious example). They are given time to decide on participation and are provided supportive and unbiased guidance from a teacher or guidance counsellor with training regarding intersex issues. This support should extend beyond when the content has been covered to deal with any issues that might arise for them. The student should be consulted regarding future educative activities.

7 The needs of intersex people in NSW anti-discrimination law

While respecting the terms of reference of the Joint Select Committee inquiry, we note that the *Anti-Discrimination Act 1977 (NSW)* provides no protections from discrimination for people with intersex variations. We respectfully wish to make the following brief comments in relation to this lacuna.

Legislation enacted in 1996 in New South Wales introduced protections on grounds of being transgender into the *Anti-Discrimination Act 1977 (NSW)*. That legislation refers to people of 'indeterminate sex' as being transgender when identifying and living as 'a particular sex', and subject to particular forms of protection from discrimination when changing sex marker on the basis of irreversible 'sexual reassignment surgery' (New South Wales 1996; Anti-Discrimination Board of New South Wales and NSW Department of Justice 2018).

We have never been able to clearly ascertain from State institutions the relevance of such a framework to people with intersex variations who are invariably determined as female or male at birth in Australia, nor the implications of the requirement for surgery on existing and pervasive medical practices that modify the bodies of infants and children to make them appear more typically female or male (Intersex Human Rights Australia 2018; Human Rights Committee 2017; Committee on the Elimination of Discrimination against Women 2018; Committee on the Rights of the Child 2019; Committee on the Rights of Persons with Disabilities 2019).

It is unclear how this provision can offer protection from discrimination to infants and children with intersex variations who have received a determination of sex recorded on their birth certificate but who lack the age and agency to freely express any identity. Further, it is unclear how this provision has relevance to individuals with intersex variations who do not change sex marker and who have no wish or intention to do so.

In line with the Darlington Statement (AIS Support Group Australia et al. 2017), an Australian-Aotearoa/New Zealand community declaration published in 2017, we call for protections from discrimination on grounds of 'sex characteristics', where this term is defined in the Yogyakarta Principles plus 10 as '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).

Protections on the ground of 'sex characteristics' have been adopted internationally, in the ACT (Minister for Justice, Consumer Affairs and Road Safety 2020) and in Tasmania (Tasmanian Legislation Online 2019). A proposal is also currently before the Victorian parliament in relation to this matter (Victoria 2020).

8 Appendices

With the intention of better informing committee members on intersex people, background information can be found below.

8.1 Appendix A: Who are intersex people

There are many misconceptions about intersex people and intersex variations. These have complicated policy development in Australia and they also complicate comprehension of intersex people by a range of community bodies and institutions. In particular, and perhaps because of poor language use and conflation of intersex with LGBT populations, intersex has frequently been imputed to mean a matter of identity rather than a matter of many diverse embodiments. Such imputations defy the experience of many people born with intersex variations, the definition of intersex in the *Sex Discrimination Act 1984 (Cth)*, and internationally widespread definitions of intersex.

Intersex variations are a natural part of human biological diversity. Intersex people are heterogeneous, but share in common risks of stigmatisation and discrimination because we were born with bodies that do not fit medical or social norms for female or male bodies. All intersex variations are biological and many have known genetic origins. A definition by the UN Office of the High Commissioner for Human Rights states:

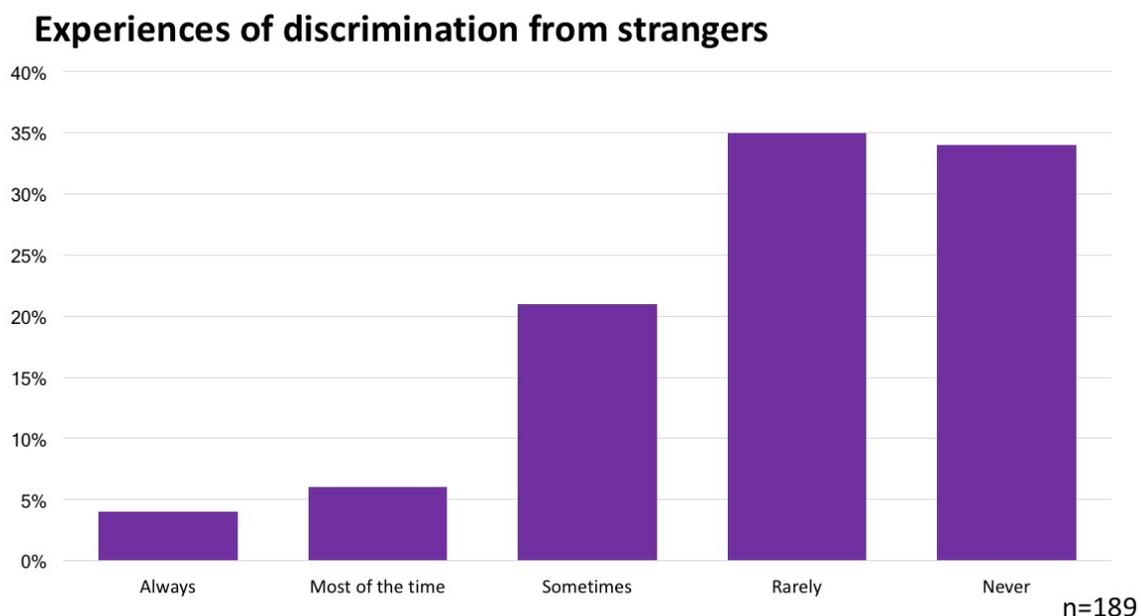
Intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit the typical definitions for male or female bodies. For some intersex people these traits are apparent at birth, while for others they emerge later in life, often at puberty. (Public statement of UN and regional human rights experts 2016).

This widely accepted definition of intersex does not specify any sex, gender, sexual orientation or gender identity. Australian and international research shows that intersex people commonly identify with legal sex assigned at birth, while many of us may not. Intersex people may identify or understand ourselves as female or male, or in other ways. Intersex people have a range of sexual orientations.

Many forms of intersex exist; it is an umbrella term, rather than a single entity. At least 40 different variations are known to science (Hiort 2013). Most variations are genetically determined, while many individuals with intersex variations have no clear genetic diagnosis (Hiort 2013). Since 2006, clinicians frequently use a stigmatising label, 'disorders of sex development' or 'DSD', to refer to intersex variations. In line with IHRA policy, the Senate has recommended that such terms not be employed (Senate of Australia Community Affairs References Committee 2013). An Australian-Aotearoa/New Zealand intersex community consensus statement, the *Darlington Statement*, regards the term DSD as problematic as it frames intersex variations as inherently disordering and in need of 'fixing' (AIS Support Group Australia et al. 2017).

Intersex variations can include differences in the number of sex chromosomes, different physical responses to sex hormones, or a different hormone balance. Some common intersex variations are diagnosed prenatally (Davis 2013). Many persons do not have clear genetic diagnoses (Eggers et al. 2016). Some individuals have received multiple different diagnoses over time.

A 2015 Australian sociological convenience sample of 272 people born with atypical sex characteristics found that 19% favoured 'X' or non-binary classifications. At the same time, 60% used the term intersex to describe themselves, including people who 'are' intersex and people who 'have' intersex variations or conditions: respondents engaged in code-switching, using different language to describe their sex characteristics in different contexts. 3% used the medical term 'disorders of sex development' to describe their sex characteristics to themselves, while 21% used this term when accessing medical services (Jones 2017).



Data from the same study also suggest that individuals whose intersex variations are more physically evident to strangers are more likely to bear the brunt of social discrimination. 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.

For people with intersex variations that are easy to hide or that are not physically evident to strangers, and for heterosexual, non-transgender people born with intersex variations, lack of legislative protections in NSW for people with intersex variations effectively create a situation of 'don't ask, don't tell'. Where an intersex variation is not evident, an individual is likely to avoid disclosure or medicalise their intersex trait to prevent discrimination.

8.1.1 Some examples of intersex variations

The purpose of this section is to provide sufficient understanding to enable consideration of the impact of policies, policy proposals, and practices affecting people born with intersex

variations. Several distinct intersex variations are detailed due, in some cases, to their higher frequency, and in one case due to the existence of relevant recent Family Court decisions.

8.1.1.1 Klinefelter syndrome/47,XXY

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 intersex variations, innate characteristics may be stigmatised. Men with Klinefelter syndrome have poorer socioeconomic outcomes (Skakkebaek, Wallentin, and Gravholt 2015). A 2015 clinical review states that 90% of people with Klinefelter syndrome are diagnosed after age 15, and only a quarter of individuals with this variation are ever diagnosed. It is possible that persons with XXY who are not diagnosed may escape some shame, stigma and health risks associated with the variation; alternatively, they may suffer in silence. 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, individuals who are not can face additional challenges in accessing appropriate medical care.

8.1.1.2 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 identify as women and a high proportion are heterosexual (Warren 2017). People with partial AIS grow up to understand themselves in diverse ways and include many women and girls with a typical female phenotype. 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 will never 'virilise' ('masculinise') if their gonads are retained or if they take testosterone replacement therapy. Women and girls with partial AIS may experience some virilisation if their gonads are retained or if they take testosterone replacement therapy depending on the degree of insensitivity to androgens. Women with 'higher grades' of partial AIS have limited capability for virilisation.

Once diagnosed, women 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 in 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.

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 intersex 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 (formerly known as the IAAF) in recent years (International Association of Athletics Federations 2019).

8.1.1.3 Congenital adrenal hyperplasia

Children with congenital adrenal hyperplasia (CAH) may necessitate immediate medical attention from birth to manage salt wasting. Children with XX chromosomes (typically associated with women) may also have genitalia that appears 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 the Department of Health and Human Services in Victoria states:

Girls with CAH may need surgery to reduce the size of the clitoris to normal, separate the fused labia and enlarge the vaginal entrance. The technical name for this operation is ‘clitoral recession or reduction and vaginoplasty’. It is done either in one or two stages.

The clitoral reduction or recession is done in the first few months of life. The vaginoplasty is sometimes done at the same time as the clitoral reduction, but may be left until adolescence, before the menstrual periods begin (Department of Health & Human Services 2014).

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).

8.1.1.4 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 (World Health Organization 2020).

The Australasian Paediatric Endocrine Group supports such interventions, even while advising the Senate in 2013 how 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'. This means that children subjected to feminising genitoplasties may not be girls at all.

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 on the basis of female gender assignment, and not due to 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]), which differs from current clinical papers focused on sterilisation associated with female gender assignment.

In 2016, in the Family Court case *Re: Carla (Medical procedure)*, a judge approved the sterilisation of a 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]) (Carpenter 2017). This does not accord with the German experience. The judge described 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]) sometimes termed a ‘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, intersex girls are exempt from such protections. The gender stereotyping evident in *Re: Carla* demonstrates a moral hypocrisy in such exemptions.

8.2 Appendix B: Community priorities

Community priorities are set out in the *Darlington Statement*. This 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, anti-discrimination law, sex markers, and education.

8.2.1 Bodily integrity

Community demands include:

- ***prohibition as a criminal act of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent***
- ***mandatory independent access to funded counselling and peer support [including integration within multidisciplinary teams in hospitals]***
- ***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)***

None of these demands are currently met. Forced and coercive medical interventions persist. The surgery on ‘Carla’ detailed in the Family Court case *Re: Carla* is not unique.

A 2014 Department of Health Medicare Benefits Schedule Review on ‘vulvoplasties’¹ identifies 371 Medicare-funded vulvoplasties for ‘congenital malformations’ during the period 2007/8 to 2011/2; an average of 74.2 per year (Department of Health 2014). Medicare procedures data published by the Australian Institute of Health and Welfare (AIHW) show an average of 71.5 vulvoplasties per year in children aged under 15 between 2002/3 and 2014/5, with a range from 57 to 95 procedures per year (Australian Institute of Health and Welfare 2017). These data are not associated with diagnostic data or claimed rationales for interventions.

The same AIHW data also show that the numbers of vulvoplasties in the 0-19 year age groups have increased significantly from 101 in 2002/3 to 258 in 2015/5.

The number of masculinising surgeries shows no particular trend over the period from 2002/3 to 2014/5. Of particular note, the Institute reports 200 *repeat* surgeries on persons aged under 20 for ‘repair of postoperative urethral fistula’ in 2013/4, including 125 such repeat procedures in children aged 1 to 4 years. To be clear, these are follow-up surgeries for iatrogenic conditions, caused by prior medical intervention.

Research published in 2018 shows that there is no evidence of any reduction in the number of surgeries relevant to children born with intersex variations over the period 2002/3 to 2014/5 (Carpenter 2018b).

8.2.1.1 Bodily integrity and international law

The right to security of the person, including freedom from injury to the body and the mind, or bodily and mental integrity are protected by the first substantive right in the *Universal Declaration of Human Rights*, article 3, as well as the *International Covenant on Civil and Political Rights*, article 9, and the *Convention on the Rights of Persons with Disabilities*, article 17 (Committee on Civil and Political Rights 2014, para. 3; United Nations 2006).

States have an obligation to eliminate forced, coercive, and unnecessary medical interventions to modify variations of sex characteristics, and violence against intersex persons. For example, in October 2016, UN agencies and experts, and regional institutions, made the following joint statement:

States must, as a matter of urgency, prohibit medically unnecessary surgery and procedures on intersex children. They must uphold the autonomy of intersex adults and children and their rights to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment. Intersex children and their parents should be provided with support and counselling, including from peers.

Intersex children and adults should be the only ones who decide whether they wish to modify the appearance of their own bodies – in the case of children,

¹ Defined in the Review as ‘any surgery performed on the outside female genital structures’

when they are old or mature enough to make an informed decision for themselves...

States should investigate human rights violations against intersex people, hold those found guilty of perpetrating such violations accountable and provide intersex people subjected to abuse with redress and compensation (Public statement of UN and regional human rights experts 2016).

Reflecting developments in international law, the 2017 *Yogyakarta Principles plus 10* on the application of international human rights law in relation to sexual orientation, gender identity, gender expression and sex characteristics state in Principle 32 that:

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).

In 2015, Malta became the first jurisdiction to protect the rights to bodily integrity of intersex and other children. The legislation prohibits non-essential modifications to children's sex characteristics, provides for oversight of decision making on cases where necessity is claimed, and provides for the development of standards of care (Malta 2018).

IHRA made a submission to the UN Human Rights Committee regarding current practices in Australia and our country's obligations under the *International Covenant on Civil and Political Rights*, and the Committee's Concluding Observations in 2017 stated:

25. The Committee is concerned that infants and children born with intersex variations are sometimes subject to irreversible and invasive medical interventions for purposes of gender assignment, which are often based on stereotyped gender roles and are performed before they are able to provide fully informed and free consent (arts. 3, 7, 9, 17, 24 and 26).

26. The State party should give due consideration to the recommendations made by the Senate Standing Committee on Community Affairs in its 2013 inquiry report on involuntary or coerced sterilisation of intersex people, and move to end irreversible medical treatment, especially surgery, of intersex infants and children, who are not yet able to provide fully informed and free consent, unless such procedures constitute an absolute medical necessity (Human Rights Committee 2017).

The cited articles of the *International Covenant on Civil and Political Rights* are on non-discrimination (articles 3 and 24), protection from torture and experimentation (article 7),

the right to liberty and security (article 9), privacy (article 17), and equality before the law (article 26). These citations highlight the many ways in which current medical practices violate our human rights. In 2018, the Committee on the Elimination of Discrimination against Women called for Australia to enact specific legal protections (2018, para. 26). In September this year, the Committee on the Rights of Persons with Disabilities made a similar call (2019, para. 34).

8.2.1.2 Bodily integrity in Australia

In 2013, as part of a broader inquiry on the involuntary or coerced sterilisation of people with disabilities in Australia, the Senate Community Affairs Reference Committee published a report on the involuntary or coerced sterilisation of intersex people in Australia. It called for substantive changes to medical practices to protect the rights of children. Amongst its statements, the cross-party report stated that:

3.107 ... there is no medical consensus around the conduct of normalising surgery...

3.128 ... Normalising appearance goes hand in hand with the stigmatisation of difference... There is frequent reference to 'psychosocial' reasons to conduct normalising surgery. To the extent that this refers to facilitating parental acceptance and bonding, the child's avoidance of harassment or teasing, and the child's body self-image, there is great danger of this being a circular argument that avoids the central issues... Irreversible medical treatment, particularly surgery, should only be performed on people who are unable to give consent if there is a health-related need to undertake that surgery, and that need cannot be as effectively met later, when that person can consent to surgery. (Senate of Australia Community Affairs References Committee 2013)

The recommendations of the cross-party report have not been implemented in any Australian jurisdiction. In a response to the report, the federal government approvingly cited non-binding and abstract guidelines produced in Victoria (Attorney General's Department 2015b). However, the guidelines appear to be disregarded in that State (Intersex Human Rights Australia 2019).

8.2.2 Anti-discrimination law

Contemporaneously with the Senate inquiry on involuntary or coerced sterilisation, Australia was the first country to introduce standalone protection for intersex people from discrimination in access to services and employment, through welcome cross-party support for amendments to the *Sex Discrimination Act 1984* in 2013. Intersex status is defined in the amended Act:

Intersex status means the status of having physical, hormonal or genetic features that are: (a) neither wholly female nor wholly male; or (b) a combination of female and male; or (c) neither female nor male.

As with the UN definition of intersex, this Australian legal definition refers to *features* or characteristics. It does not specify any legal sex, sexual orientation or gender identity. According to the explanatory memorandum for the amending bill, the attribute was not intended to create a third sex (House of Representatives and Australia 2013).

Unfortunately, changes to anti-discrimination law in 2013 have, however, been imputed to imply matters of identity (Yoosuf 2015). These misinterpretations have unfortunately been given impetus by poorly-formed federal guidelines on the recognition of sex and gender that simultaneously recognise that intersex people may be female, male or identify otherwise as 'X', and also include the word intersex within a definition of 'X' (Attorney General's Department 2015a). In a positive move to respond to this issue, Australian Standard AS4590 on data interchange now defines 'X' gender as 'non-binary'.

Many submissions to the inquiry may unfortunately reflect these misconceptions, for example, through a framing of issues affecting 'LGBTI' populations or an 'LGBTI community' as issues of sexuality and gender diversity. Perhaps the most challenging effect of such misunderstandings is that they have made intersex more incomprehensible or obscured. We invite the inquiry to carefully examine submissions that extrapolate the characteristics and needs of an intersex population from an exclusive or primary analysis of the characteristics and needs of LGBT people.

Internationally, a different attribute of 'sex characteristics' has been implemented in law by multiple national governments to protect intersex and other people from discrimination and violence (Malta 2018). This attribute has been cited by the Asia Pacific Forum of National Human Rights Institutions (Asia Pacific Forum of National Human Rights Institutions 2016), and a major 2017 supplement to the *Yogyakarta Principles* on the application of international human rights law in relation to sexual orientation, gender identity, gender expression and sex characteristics.² Use of this updated attribute is also supported by the Darlington Statement (AIS Support Group Australia et al. 2017) for several reasons, including that it usefully cannot be imputed as a matter of identity rather than embodiment.

The *Darlington Statement* calls for access to reasonable accommodations in education and employment, including 'special needs requirements, workplace adjustments, job access assistance, and provisions for medical leave' (2017, para. 57).

8.2.3 Sex markers

An involuntary consignment of intersex persons in Australia to a *de facto* third or non-binary status has occurred since the annulment of the marriage of a man deemed a 'true hermaphrodite', based on an ahistorical appeal to marriage 'as understood in Christendom', in the 1979 Family Court of Australia case *In the marriage of C and D (falsely called C) (1979)*

² The *Yogyakarta Principles plus 10* defines 'sex characteristics' as follows: 'UNDERSTANDING "sex characteristics" as 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'

FLC 90-636. Some individuals (intersex and non-intersex) have freely chosen third or non-binary sex markers since 2002/3 (Butler 2003).

Current federal guidelines (Attorney General's Department 2015a), South Australian regulations (Consumer and Business Services 2017) and ACT regulations (Office of Regulatory Services and Australian Capital Territory Government 2014) position intersex within a third sex/gender category. In response to involuntary association with third sex markers, the *Darlington Statement* declares that:

8. Regarding sex/gender classifications, sex and gender binaries are upheld by structural violence. Additionally, 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. Undue emphasis on how to classify intersex people rather than how we are treated is also a form of structural violence. (AIS Support Group Australia et al. 2017)

A persistent harmful framing of intersex as a third sex classification, together with diverse personal preferences while sex classifications remain stated on legal identification documents, led to a declaration that 'The larger goal is not to seek new classifications but to end legal classification systems and the hierarchies that lie behind them':

- a. *As with race or religion, sex/gender should not be a legal category on birth certificates or identification documents for anybody.*
- b. *While sex/gender classifications remain legally required, sex/gender assignments must be regarded as provisional. Given existing social conditions, we do not support the imposition of a third sex classification when births are initially registered.*
- c. *Recognising that any child may grow up to identify with a different sex/gender, and that the decision about the sex of rearing of an intersex child may have been incorrect, sex/gender classifications must be legally correctable through a simple administrative procedure at the request of the individual concerned.*
- d. *Individuals able to consent should be able to choose between female (F), male (M), non-binary, alternative gender markers, or multiple options. (AIS Support Group Australia et al. 2017)*

In respect of the long-term aspirational goal stated here, we note that Australian governments are increasingly relying on, and sharing, biometric data, and a call to end sex markers on legal identification documents has no consequences for the census and other surveys beyond those caused by the absence of racialised and religious classifications on identification documents.

Reforms to at least end construction of intersex as a third category require change to current federal guidelines on recognition of sex and gender (Attorney General's Department 2015a). Since early 2015, we have (jointly with a range of other organisations) asked the

government to change the definition of X from ‘indeterminate/intersex/unspecified’ to ‘non-binary’, as a minimum reform of current standards (National LGBTI Health Alliance et al. 2015). IHRA has also made submissions to ACT, NSW and SA governments on this matter, prior to establishment of such regulations (Briffa 2013; Carpenter and Organisation Intersex International Australia 2017; Intersex Human Rights Australia 2020).

The recent federal Style Manual and new ABS Standard on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation better model the relationship between sex and sex characteristics (Australian Government 2020; Australian Bureau of Statistics 2021).

8.2.4 Education

In relation to education about intersex variations and disclosure to individuals, the Darlington Statement says:

54. We call for the inclusion of accurate and affirmative material on bodily diversity, including intersex variations, in school curricula, including in health and sex education.

55. We call on education and awareness providers to develop content with intersex-led organisations, and promote delivery by intersex people.

In relation to support within the school environment:

53. We acknowledge the impacts of stigma, trauma and unwanted medical interventions on access to education and on employment, and consequences that include high rates of early school leaving, poverty, self-harm and suicidality.

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.

In relation to physical education and sport at school:

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 relation to the distinctiveness of intersex from other issues, and a need for supported age-appropriate disclosure:

47. Intersex is distinct from other issues. We call on allies to actively acknowledge our distinctiveness and the diversity within our community, to support our human rights claims and respect the intersex human rights

movement, without tokenism, or instrumentalising, or co-opting intersex issues as a means for other ends. "Nothing about us without us."

28. Children with intersex variations require clear, age-appropriate disclosure of their intersex variations, and affirmative support, including peer support.

We invite the committee to consider these issues.

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