
# Response to the Development of a whole-of-government Trauma Strategy for Queensland

## Submission by Intersex Human Rights Australia (IHRA)

May 2024

# Contents

# 1 Introduction

Thank you for the welcome opportunity to respond to the discussion papers released by the Queensland Mental Health Commission on the development of a whole-of-government Trauma Strategy for Queensland. The propose strategy will have enormous positive impact for the intersex community members in Queensland through addressing many of the drivers of trauma at various life stages, resulting in poorer physical health and psychosocial outcomes

We confine our submission to the following consultation question, and also take the opportunity to address related issues that we have raised previously with the Queensland Mental Health Commission:

- What stood out to you from the discussion paper or papers your read? Please explain why.
- What should be the key focus areas of the Queensland trauma strategy to prevent, address and reduce the impact of trauma effectively?
- What specific actions or strategic priorities do you recommend for addressing trauma more effectively?

Related issues include a need to harmonise currently incoherent understandings of people with innate variations of sex characteristics within all government agencies and their respective portfolios, in line with an existing national statistical standard,[1] public government commitment,[2] and a report of the Australian Human Rights Commission.[3]

## 1.1 About this submission

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

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

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

[2] 'Re: Fair Work Act'Letter from Tony Burke, 22 December 2022 see section 5.

[3] Australian Human Rights Commission, *Ensuring Health and Bodily Integrity: Towards a Human Rights Approach for People Born with Variations in Sex Characteristics* (Australian Human Rights Commission, 2021) <https://humanrights.gov.au/intersex-report-2021> ('*Ensuring Health and Bodily Integrity*').

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.[4] Together with Intersex Peer Support Australia (IPSA, also known as the AIS Support Group Australia) we comprise the Darlington Consortium.

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

## 1.2 Authorship

This submission by IHRA has been written by Bonnie Hart and Dr Morgan Carpenter, with support from the IHRA board.

Bonnie Hart (she/her) is a proud intersex woman, peer worker, and systemic advocate working with and within the intersex community. Bonnie is the Deputy Executive Director of Intersex Human Rights Australia and the designer and Manager of InterLink. Bonnie coordinates intersex community initiatives including the Darlington Statement, an Aotearoa/New Zealand and Australian intersex community consensus statement and the YellowTick intersex education initiative. Bonnie is currently undertaking a PhD in Psychology at the University of Southern Queensland.

Dr Carpenter has a PhD in bioethics (Sydney). He is Executive Director of IHRA and a Research Affiliate at University of Sydney School of Public Health. He is a member of an expert advisory group for a 10-year action plan on LGBTIQA+ health and wellbeing, chaired by Assistant Minister for Health and Aged Care, the Hon. Ged Kearney. He is also the member of reference groups for the Australian Bureau of Statistics and NSW Health.

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

# 2 Nomenclature and framing

## 2.1 Intersex and (innate) variations of sex characteristics

Innate variations of sex characteristics is a descriptive term for intersex variations. The term originates in a 2019 report by the UN Office of the High Commissioner for Human Rights which states (our emphasis):

> *"Intersex" is an umbrella term used to describe a wide range of **innate** bodily **variations in sex characteristics**. "Intersex" people are born with sex characteristics that do not fit typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns.*[5]

This normative definition has been incorporated into other definitions and data models around the world, including in Australia.

The Australian Bureau of Statistics (ABS) publish a nominal definition of "variations of sex characteristics" in the Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, defining it as innate, and identifying intersex and other terms as synonyms:

> *Variations of sex characteristics refers to people with innate genetic, hormonal or physical sex characteristics that do not conform to medical norms for female or male bodies. It refers to a wide spectrum of variations to genitals, hormones, chromosomes and/or reproductive organs.*
>
> *Other umbrella terms used to describe being born with variations of sex characteristics are intersex or Differences/Disorders of Sex Development (DSD).*[6]

The ABS Standard also elaborates the relationship between sex and sex characteristics, where sex is typically observed and registered based on observed sex characteristics:

> *A person's sex is based upon their sex characteristics, such as their chromosomes, hormones and reproductive organs. While typically based upon the sex characteristics observed and recorded at birth or infancy, a person's reported sex can change over the course of their lifetime and may differ from their sex recorded at birth.*[7]

## 2.2 Sex determination and sex registration

Multiple different models of sex determination have been employed over the lifespans of people currently alive and living in Australia, including:

- Phenotype (observable traits and appearance)
- micturition (method of urination)
- gonads
- chromosomes
- existence of an SRY protein
- gametes (or the gametes that might be produced under different material circumstances to those produced by innate variations or medical treatment, including medical treatment without personal informed consent)

[5] OHCHR, *Human Rights Violations Against Intersex People: A Background Note* (24 October 2019) <https://www.ohchr.org/en/documents/tools-and-resources/background-note-human-rights-violations-against-intersex-people>.
[6] Australian Bureau of Statistics (n 1).
[7] Ibid.

- cluster approaches that that a combination of factors into account

For endosex people (people without innate variations of sex characteristics) these different methodologies do not produce different outcomes, but for many people with innate variations of sex characteristics they can do.

Irrespective, no model of sex determination is capable of accounting for the diverse actual methods of sex determination applied in the cases of people with innate variations of sex characteristics.

Furthermore, sex registration is a separate step where different rules are applied in cases where an innate variation of sex characteristics is evident. A choice of F or M is not *per se* the problem that we have with this medicalised process. In a 2022 textbook, UK paediatric endocrinologists Ahmed and Ali give an overview of factors in all cases, identifying the diagnosis and a range of other (sometimes consequential) factors:

> *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*[8]

In a 2020 journal article, NSW paediatric endocrinologists focus on cases where there is a dilemma, assuming that diagnosis has been identified (knowing the diagnosis will eliminate a dilemma in many cases):

> *Sex 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*[9]

As is evident from the two sources, some subjective factors are inherent to sex assignment for people with identified innate variations of sex characteristics. These include "surgical options", i.e. either feminising or masculinising surgery. Where they occur without evidence of urgent necessity or personal informed consent, feminising or masculinising surgeries are human rights violations.[10] Nevertheless they occur routinely in Australia and internationally. We present evidence on these issues in the appendix to this submission. The agency and choices of people with innate variations of sex characteristics are often constrained and impacted by the ways we have been treated by medicine without our personal informed consent.

Several factors arise out of this discussion.

Firstly, to have an intersex variation does not mean that someone has changed gender from what was assigned at birth. Nor does it mean that individuals identify as neither male nor female. These are misconceptions.

While having an innate variation of sex characteristics does not make someone transgender or gender diverse, the most widespread and popular misconceptions about intersex people conflate our population with transgender and gender diverse populations. This means that, irrespective of

[8] S Faisal Ahmed and Salma R Ali, 'Disorders of Sex Development (DSD) in the Newborn' in John AH Wass, Wiebke Arlt and Robert K Semple (eds), *Oxford Textbook of Endocrinology and Diabetes 3e* (Oxford University Press, 3rd edition, 2022) 1169.
[9] Komal A Vora and Shubha Srinivasan, 'A Guide to Differences/Disorders of Sex Development/Intersex in Children and Adolescents' (2020) 49(7) *Australian Journal of General Practice* 417.
[10] Australian Human Rights Commission (n 3); OHCHR (n 5).

whether or not someone with a variation is gender diverse, we can find ourselves treated as if we all are, and this is likely to be evident in many submissions in response to the consultation paper.

Secondly, our population is heterogeneous and intersectional. Different innate variations of sex characteristics are associated with different typical ages of diagnosis, and different sex registration or so-called "dilemmas". Our population includes infants, children and adolescents; women, men and non-binary people; people who live in and identify with sex registered at birth and people who do not.

Finally, we believe that it is always unethical to reassign people, against their wishes, from one sex category to another in line with one or other model of sex determination. This means that sex registered at birth should be respected in legislation, regulation, policy and guidelines in all cases unless, on an individual basis, an individual specifies otherwise.

## 2.3 A need to harmonise incoherent frameworks used by the Queensland Government

In our 2012 submission to a public consultation on the then proposed *Human Rights and Anti-Discrimination Bill*, we sought to extract provisions purporting to represent intersex people from a proposed attribute of gender identity.[11] We sought protections from discrimination on grounds of sex characteristics or intersex status, noting that neither would create a third sex.[12] A later amendment to the Sex Discrimination Act ("SDA") provided for protections on grounds of intersex status. The attribute was selected opportunistically as prior proposals using this attribute were already under discussion in Tasmania. The explanatory memorandum notes that the definition of intersex status "is not intended to create a third sex in any sense".[13]

Despite this careful construction, references to intersex status have typically conflated intersex with a third sex, or have constructed intersex as an identity.[14] Therefore, and in particular from the development of the Darlington Statement in 2017, we have sought protections on grounds of sex characteristics.[15] Such protections have now been enacted in the ACT, Northern Territory, Queensland, Tasmania and Victoria with proposals also before the NSW Parliament.

Despite recognition that law reform in 2013 was not intended to create a third sex, 2013 guidelines on sex and gender published by the Attorney General's Department have unfortunately created a third gender associated with intersex traits.[16] This was a perverse outcome. Additionally, the guidelines contain a contradiction:

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[11] Morgan Carpenter, *Submission on the Exposure Draft of the Human Rights and Anti-Discrimination Bill, 2012* (21 December 2012).
[12] Ibid.
[13] House of Representatives, Explanatory Memorandum, Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013 2013.
[14] See Morgan Carpenter, *Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data* (University of Huddersfield, May 2022) <http://www.intersexnew.co.uk/wp-content/uploads/2023/04/Morgan-Carpenter-MNC-publication-version-aihw-paper.pdf>; for example, Dean Smith, Explanatory Memorandum: Marriage Amendment (Definition and Religious Freedoms) Bill 2017 2017.
[15] AIS Support Group Australia et al (n 4).
[16] Attorney General's Department, *Australian Government Guidelines on the Recognition of Sex and Gender (2015)* (2015) <http://www.ag.gov.au/Publications/Pages/AustralianGovernmentGuidelinesontheRecognitionofSexandGender.aspx>.

- On the one hand paragraph 12 identifies that the population of people with innate variations of sex characteristics is diverse, in the statement "Intersex people have a diversity of bodies and gender identities, and may identify as male or female or neither."[17]
- On the other hand, a third gender classification, "X", is defined as "Indeterminate/Intersex/Unspecified". This does not respect the diversity in our population, and it constructs both intersex and the sometimes related term 'indeterminate' (derived from the International Classification of Diseases)[18] as gender identities. The assumption is that being intersex makes a person inherently part of a third gender.[19]

To resolve this contradiction, and documented since 2015,[20] IHRA and other organisations have called repeatedly and regularly for the definition of "X" to be changed from "Indeterminate/Intersex/Unspecified" to non-binary, or for the definition to otherwise remove all associations with innate variations of sex characteristics.

Another significant example of conflation of intersex with gender identity is the creation of multiple new sex classifications for birth registrations in most States and Territories over the last decade. It is not appropriate to conflate these with intersex. Just two jurisdictions have created sex classifications named intersex for birth registration (the ACT and South Australia). In both cases we opposed the creation of these classifications,[21] for sound reasons: for the period for which the ACT government has been able to provide data, those data confirm **that no children have been assigned to this classification**. Infants have, however been assigned to other new categories of sex. We believe that this population predominantly comprises endosex (non-intersex) children.

## 2.4 Prohibiting harmful practices

As is evident from the material included in the appendix (Section 4), harmful medical practices persist in Australia on infants, children, adolescents and adults with innate variations of sex characteristics resulting in medical and system-induced trauma. Recommendations for action by the Senate Community Affairs References Committee, the 2017 intersex community consensus statement (the Darlington Statement),[22] UN Treaty Bodies, and the Australian Human Rights Commission set out a model for reform. The former government has failed to act, despite these actions and clear evidence of harm. For example:

the sterilisation of a child was authorised in the judgement of a 2016 Family Court case where the judge referred to a history of feminising surgeries on an infant as surgeries that "enhanced the appearance of her female genitalia"; that surgical history had not been the subject of court oversight. Moreover, the judge ruled that invasive irreversible surgical and medical interventions on children with innate variations of sex characteristics did not require court authorisation, but could be consented to by parents.

[17] Ibid.
[18] Carpenter, 'Ambivalent Attention and Indeterminate Outcomes: Constructing Intersex and DSD in Australian Data' (n 14).
[19] Attorney General's Department (n 16).
[20] 'RE: Commonwealth Attorney-General's Department Review of the Australian Government Guidelines on the Recognition of Sex and Gender'Letter from National LGBTI Health Alliance et al, 24 September 2015 <https://ihra.org.au/30043/joint-submission-federal-sexgender-guidelines/>.
[21] see, for example, Morgan Carpenter, 'The "Normalisation" of Intersex Bodies and "Othering" of Intersex Identities' in Jens Scherpe, Anatol Dutta and Tobias Helms (eds), *The Legal Status of Intersex Persons* (Intersentia, 2018) 445.
[22] AIS Support Group Australia et al (n 4).

In 2019, a Queensland Paediatric and Adolescent Gynaecology Clinic published evidence that all children presenting to that clinic with similar traits or so-called ambiguous genitalia underwent feminising surgeries and sterilisations, which we expect occurred soon after diagnosis. For example:

> *Gonadectomy and feminizing genitoplasty 1 year age. Vaginal dilatation. [PAIS] Gonadectomy and genitoplasy [sic] as infant. Pubertal induction and HRT. Vaginal Dilatation. [Mixed gonadal dysgenesis]*
> *Gonadectomy and reconstructive surgery as infant. Pubertal induction and HRT. Vaginal dilatation. [PAIS]*
> *Gonadectomy and surgical creation neovagina in adolescence. Pubertal induction and HRT. Vaginal dilators. [5 alpha reductase deficiency – age of surgery in adolescence and the person providing consent are not disclosed]*
> *Gonadectomy and surgical creation neovagina as child. Pubertal induction and HRT. Vaginal dilatators. [PAIS]*
> *Gonadectomy and feminizing surgery age 2yo. Pubertal induction and HRT. Vaginal dilatation. [PAIS]*
> *Bilateral orchidectomy and hernia repair aged 12. Pubertal induction and HRT. Vaginal dilatation. [17β-hydroxysteroid dehydrogenase 3 deficiency]*
> *Bilateral gonadectomy. Pubertal induction and HRT. Vaginal dilatation. [PAIS]*[23]

The United Nations Office of the High Commissioner for Human Rights has expressed concern that "Loose conceptions of medical necessity or therapeutic treatment may facilitate social and cultural rationales, and other rationales that lack evidence of urgent need".[24] It is unfortunate that the then Australian government asserted in 2021 that "Court authorisation is required for any surgical or sterilisation procedure that is not medically necessary for children with intersex characteristics".[25] This statement is not borne out in evidence from the 2016 Family Court case regarding surgical interventions that "enhanced the appearance" of female genitalia prior to the court case, nor subsequent clinical reports described above.

As we show below, the ACT has already legislated to eliminate harmful practices on people with innate variations of sex characteristics in medical settings, and the Victorian government expects to introduce legislation into its State Parliament during 2024.

In 2021, the Australian Human Rights Commission (AHRC) made 12 recommendations in a report, '*Ensuring health and bodily integrity*', aimed at ensuring a human rights-based approach to decision-making on medical interventions. The report builds on recommendations of an earlier Senate committee inquiry on the *'Involuntary or coerced sterilisation of intersex people'*.[26] It also builds on the following demands in the Darlington Statement:

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[23] T Adikari et al, 'Presentations and Outcomes of Patients with Disorders of Sexual Development (DSD) in a Tertiary Paediatric and Adolescent Gynaecology (PAG) Service' (at the RANZCOG Annual Scientific Meeting 2019, Melbourne, 2019) <https://ranzcogasm.com.au/wp-content/uploads/2019/10/243.pdf>.
[24] OHCHR (n 5).
[25] Working Group on the Universal Periodic Review, *Report of the Working Group on the Universal Periodic Review Australia Addendum Views on Conclusions and/or Recommendations, Voluntary Commitments and Replies Presented by the State under Review* (No A/HRC/47/8/Add.1, Human Rights Council, 2 June 2021).
[26] Senate of Australia Community Affairs References Committee, *Involuntary or Coerced Sterilisation of Intersex People in Australia* (2013) <http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index>.

> *7. We call for the immediate **prohibition as a criminal act** of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent. We call for freely-given and fully informed consent by individuals, with individuals and families having mandatory independent access to funded counselling and peer support.*
>
> *22. We call for the provision of alternative, independent, effective **human rights-based oversight mechanism(s)** to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations. The pros and cons for and against medical treatment must be properly ventilated and considered, including the **lifetime health, legal, ethical, sexual and human rights implications**.*[27]

Some early surgical interventions are necessary for physical health and well-being, or elective and permissible with personal informed consent, but many are justified through appeals to gender stereotypes, medical eminence, and overly loose conceptions of medical necessity and therapeutic treatment, all of which are presented as rationales for treatment that is consented to by parents or carers. [28]

Doctors specialising in aspects of physical health have argued that psychosocial factors and mental health are appropriate reasons for early surgical intervention, but professional bodies of psychiatrists and psychologists have rejected these rationales.[29]

Additionally, the AHRC report found it necessary to refute a persistent straw man argument, that some advocates want 'a complete moratorium on all genital/gonadal surgery until the individual is able to give informed consent'.[30] Citing a submission by the Australasian Paediatric Endocrine Group, the AHRC commented:

> *Some stakeholders seemed to base their opposition to any legal sanctions on the premise that all medical interventions modifying sex characteristics would be prohibited, in all circumstances. However, neither the Commission nor any stakeholders have advocated such a blanket prohibition.*[31]

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

> *There is real risk that, without changes to oversight mechanisms, interventions will continue to be made that are not medically necessary and which could have been deferred under a*

[27] AIS Support Group Australia et al (n 4).
[28] Australian Human Rights Commission (n 3).
[29] Ibid.
[30] Mike O'Connor, 'The Treatment of Intersex and the Problem of Delay: The Australian Senate Inquiry into Intersex Surgery and Conflicting Human Rights for Children' (2016) 23(3) *Journal of Law and Medicine* 531; Vora and Srinivasan (n 9); Komal A Vora et al, 'Role of Cross-campus Multidisciplinary Team Meetings in Decision-making for Children and Adolescents with Differences of Sex Development/Intersex' (2021) 57 *Journal of Paediatrics and Child Health* 1402; 'ACT Variations in Sex Characteristics (Restricted Medical Treatment) Bill 2022'Letter from Royal Australasian College of Surgeons Health Policy and Advocacy Committee, 17 July 2022 <https://www.surgeons.org/News/Advocacy/ACT--Variations-in-Sex-Characteristics-Restricted-Medical-Treatment-Bill-2022>; Morgan Carpenter, 'Fixing Bodies and Shaping Narratives: Epistemic Injustice and the Responses of Medicine and Bioethics to Intersex Human Rights Demands' (2024) 19(1) *Clinical Ethics* 3 ('Fixing Bodies and Shaping Narratives').
[31] Australian Human Rights Commission (n 3).

> *precautionary approach. Current practice has included interventions that are based on psychosocial rationales, such as gender-conforming treatments. […] current international and Australian clinical guidance allows clinicians to take psychosocial factors, such as cultural or social pressure, into account as relevant when considering whether an intervention should be proposed.*[32]

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

- *'Bodily integrity principle', reflecting the right of all people to autonomy and bodily integrity.*
- *'Children's agency principle', including the right to express views regarding treatment, and support to make decisions.*
- *'Precautionary principle', including deferral of treatment where safe to do so, until children can make their own decisions.*
- *'Medical necessity principle', understanding that some treatments may be urgent to avoid serious harm.*
- *'Independent oversight principle', recognising the serious consequences arising from wrong decisions.*[33]

The AHRC recommendations are in line with recommendations to Australia by UN Treaty Bodies. UN Treaty Body recommendations to Australia by the Human Rights Committee,[34] Committee on the Rights of the Child,[35] the Committee on the Elimination of Discrimination against Women,[36] and the Committee on the Rights of Persons with Disabilities[37] leave no doubt that involuntary and unnecessary medical treatments on people with innate variations of sex characteristics are discriminatory, fail to protect the integrity of the person, and are 'harmful practices' reulting in medical trauma within ongoing impacts on health and wellbeing that must be prohibited. For example, CEDAW stated to Australia in 2018:

> *The Committee urges that the State party to […] Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary surgical or other medical procedures on intersex children before they reach the legal age of consent, implement the recommendations made by the Senate in 2013 on the basis of its inquiry into the involuntary or coerced sterilization of intersex persons, provide adequate counselling and support for the families of intersex children and provide redress to intersex persons having undergone such medical procedures*[38]

[32] Ibid.
[33] Morgan Carpenter, 'Protecting Intersex People from Harmful Practices in Medical Settings: A New Benchmark in the Australian Capital Territory' (2023) 29(2) *Australian Journal of Human Rights* 409 ('Protecting Intersex People from Harmful Practices in Medical Settings').
[34] Human Rights Committee, *Concluding Observations on the Sixth Periodic Report of Australia* (No CCPR/C/AUS/CO/6, 1 December 2017).
[35] Committee on the Rights of the Child, *Concluding Observations on the Combined Fifth and Sixth Periodic Reports of Australia* (No CRC/C/AUS/CO/5-6, 1 November 2019).
[36] Committee on the Elimination of Discrimination against Women, *Concluding Observations on the Eighth Periodic Report of Australia* (No CEDAW/C/AUS/CO/8, 25 July 2018).
[37] Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Combined Second and Third Reports of Australia* (No CRPD/C/AUS/CO/2-3, 23 September 2019).
[38] Committee on the Elimination of Discrimination against Women (n 36).

The ACT government has enacted reforms to protect the human rights of people with innate variations of sex characteristics in medical settings.[39] In line with recommendations by the AHRC, it has provided for criminal penalties where contested medical interventions take place without independent oversight.[40] Independent oversight has been implemented in a new Restricted Medical Treatment Assessment Board, chaired by former National Children's Commissioner Megan Mitchell AM.[41] The ACT government has also established a hospital based paediatric psychosocial support service for people with innate variations of sex characteristics and our families.

The Victorian government has also made commitments to reform,[42] and expectations are that a bill to introduce an intersex protection scheme will be introduced into the Victorian Parliament during 2024.[43]

We need national protections, either through national legislation and regulation building on the welfare provisions of the Family Law Act, or through nationally consistent legislation and regulation.

# 3 Responses and recommendations

After reviewing the discussion papers related to life course (Pregnancy and early parenting, Infants & young people, Children, Young people / young adults) and of diverse needs and experiences (LGBTIQA+ community, People with a disability) we provide the following responses to the consultation questions:

**What stood out to you from the discussion paper or papers your read? Please explain why.**

It is obvious to us that the authors do not have a good conceptualisation of the diversity of intersex populations and the mental health and complex trauma risks for people with intersex variations of all ages. From the information provided in this submission it is evident the mechanisms contributing towards traumatic experiences, particularly in early childhood and as young people, have not been adequately addressed in any of the discussion papers. Understanding the diversity of experiences within the intersex community (including people with innate variations of sex characteristics of any age, parents and carers of children and young people with innate variations of sex characteristics, and even prospective parents undergoing genetic screening or IVF) is tantamount to addressing the poor mental health outcomes experienced by this population, including occurrence of complex post traumatic stress disorder.

Looking specifically at the LGTIQA+ community paper, there is no mention of the stigma or discrimination specific to intersex populations, including over-pathologisation, shame and secrecy, lack of information about their bodies, endosexism, impacts of non consensual medical interventions

[39] Chief Minister, Treasury and Economic Development Directorate, 'Protecting the Rights of People with Variations in Sex Characteristics in Medical Settings' (4 April 2023) <https://www.cmtedd.act.gov.au/policystrategic/the-office-of-lgbtiq-affairs/variations-in-sex-characteristics-bill>; ACT Health, 'Protecting the Rights of People with Variations in Sex Characteristics' (6 March 2024) <https://www.health.act.gov.au/services-and-programs/lgbtiq/protecting-rights-people-variations-sex-characteristics>.

[40] Carpenter, 'Protecting Intersex People from Harmful Practices in Medical Settings' (n 33).

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

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

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

(medical trauma) and lack of knowledgeable mental health services within in existing clinical management protocols or privately. The literature review has not used diverse enough terms to access literature on the population (intersex, differences of sex development, disorders of sex development, DSDs, sex characteristics, innate variations of sex characteristics, diagnostic terms etc) instead relying on LGBT+ research that fails to capture a sample that is representative of the diversity of the population, including people who identity as cis-gendered and heterosexual men or women with intersex variation, children too young to express an identity and parent of children with medical diagnoses.

Although much research exisits, for the purpose of illustration, the following data onmental health outcomes have been included :

- Psychological distress (Roen 2019)
- Lower self-rated Quality of Life (Bennecke et al. 2017) incl. children (Hansen-Moore et al. 2021)
- Suicidal ideation by adults, young people (Schweizer et al. 2016) and children (Hansen-Moore et al. 2021)
- Dsd-LIFE - psychiatric disorders (42.5%) i.e., eating disorders, chronic anxiety/depression, neurodevelopmental disorders, self-reported suicide attempts (6.8%) (Falhammer et al. 2018)
- Somatic complaints, thought disorder, attention problems, obsessive-compulsive symptoms, aggressive behavior, and interpersonal sensitivity (Godfrey 2020)
- Systematic reviews find mental health outcomes result from prior medical intervention (Godfrey 2020) based on corrective, pathological biomedical perspectives, urgency escalated without evidence that violate human rights (Machado et al. 2016)

Jones et al. (2016) found in an Australian sociological study (n=272):

- 60% received treatments on basis of sex characteristics, half at under 18 years of age
- Majority experienced at least one negative impact from treatment
- 60% had thought about suicide, 19% had attempted it

The mental health needs of people with innate variations of sex characteristics vary across the lifespan and can result in complex needs if not provided early. Medical and social discrimination during formative periods can impact education and future employment prospects. Mental health services are accessed in different context such e.g. multidisciplinary care at paediatric hospitals (Medicare/free), private clinic, community services, school counsellors, help lines, peer support.

People with innate variations of sex characteristics have intersectional forms of discrimination, resulting in traumatic experiences. For example a sample of people with Intersecting LGBTQ identities (Amos et al. 2022) found:

- 87% suicidal ideation, 52.6% attempted
- 81.6% diagnosed with depression or anxiety

Greater consultation with intersex experts, particularly those with lived experience, is required to ensure the trauma strategy is fit for the purpose of mitigating trauma across all government agencies.

**What should be the key focus areas of the Queensland trauma strategy to prevent, address and reduce the impact of trauma effectively?**

Adopting a rights-based psychosocial lens for managing innate variations of sex characteristics (intersex) within health contexts. Recognising that current biomedical frameworks for managing do not provide adequate early psychosocial intervention, legislative protections from non-consensual, deferrable medical intervention and greater oversight of current medical practices is required. Addressing the concentration of resources and emphasis on paediatric hospital services at the expense of adult and community-based services. Integration of frameworks used by various government agencies for conceptualising intersex communities and the health and mental healthcare needs of our diverse population. Elevating the voice and rights of children, preserving their fundamental rights of bodily integrity, bodily autonomy and self-determination.

Additional efforts are required to reduce the personal cost for people with intersex variations when accessing inadequate services. This could be achieved through improving the quality of psychosocial and health services generally through targeted delivery of intersex education and professional development opportunities, implementation of best practice standards within exisiting accreditation requirements.

More mechanisms to address the upstream drivers of medical and systems-induced trauma are identified in IHRA's Theory of Change - https://ihra.org.au/40737/ihra-theory-of-change/

**What specific actions or strategic priorities do you recommend for addressing trauma more effectively?**

In response to the issues presented, we make the following recommendations:

**Recommendation 1:**

In all guidelines, legislation, regulation and policy, respect the sex assigned at birth of all people with innate variations of sex characteristics unless, on an individual basis, an individual specifies otherwise.

For the current consultation, this means that legislation, regulation, policy and guidelines must treat people in line with legal sex.

**Recommendation 2:**

We recommend that the QMHC and all Queensland Government agencies align all data models, including references to sex, gender, variations of sex characteristics and sexual orientation, with the ABS Standard.

**Recommendation 3:**

Enact legislative protections for people with innate variations of sex characteristics from harmful practices in medical settings, in line with recommendations 1, 5, 8 and 9 of the Australian Human Rights Commission's 2021 report on ensuring the health and bodily integrity of people born with variations of sex characteristics.[44]

[44] Australian Human Rights Commission (n 3).

**Recommendation 4:**

Increasing state-based funding to both hospital-based psychological services and community-controlled psychosocial services directed towards people with innate variations of sex characteristics of all ages (paediatric, adolescent, adult and geriatric), including intersex peer support. This includes funding to provide care coordination for complex needs across primary/secondary health, social work, allied health services, NDIS, community services and transition from paediatric services.

**Recommendation 5:**

Improving cross-sector core awareness of intersex population and issues through targeted education informed by people with lived experience, particularly amongst health and mental health care professionals, allied health, community services and government agencies.

# 4 Appendix: Examples and experiences of innate variations of sex characteristics

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

Respondents to a large Australian sociological study of people born with atypical sex characteristics in 2015[45] had more than 35 different variations, including 5- alpha-reductase deficiency, complete and partial androgen insensitivity syndrome (AIS), bladder exstrophy, clitoromegaly, congenital adrenal hyperplasia (CAH), cryptorchidism, De la Chapelle (XX Male) syndrome, epispadias, Fraser syndrome, gonadal dysgenesis, hyperandrogenism, hypospadias, Kallmann syndrome, Klinefelter syndrome/XXY, leydig cell hypoplasia, Mayer-Rokitansky-Küster-Hauser syndrome (MRKH, mullerian agenesis, vaginal agenesis), micropenis, mosaicism involving sex chromosomes, mullerian (duct) aplasia, ovotestes, progestin induced virilisation, Swyer syndrome, Turner's syndrome/X0 (TS), Triple-X syndrome (XXX).

Below we detail the characteristics and experiences of people with several distinct innate variations of sex characteristics due, in some cases, to their higher frequency, and in one case due to the existence of relevant Family Court decisions – including a 2016 decision adjudicated in Brisbane.[46]

## 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.[47] 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

[45] Tiffany Jones et al, *Intersex: Stories and Statistics from Australia* (Open Book Publishers, 2016) <https://researchers.mq.edu.au/en/publications/intersex-stories-and-statistics-from-australia>.
[46] *Re Carla* [2016] FamCA 7
[47] Kerry Warren, 'Hormones, Experimental Surgery & Heartbreak: What It Means To Be Intersex', *Whimn* (online, 8 November 2017) <http://www.whimn.com.au/talk/think/hormones-experimental-surgery-heartbreak-what-it-means-to-be-intersex/news-story/358596586943a2d7a0f738f56f633239>.

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[48]. Following sterilisation, individuals require hormone replacement to maintain bone health, libido and general health. Recent peer-reviewed clinical journals have established that rates of gonadal tumours in people with partial AIS are also so low that they do not justify early prophylactic sterilisations[49].

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

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

> *a trend toward consideration of less genital and gonadal surgery in infants assigned female, or delaying surgery. It is important to note that current practice has changed significantly from the past'*[50]

However, we are unable to pinpoint any moment in time that divides that past from the present, and we are unaware of any Australian women with AIS aged under 50 who have not been sterilised. It was only very recently, in 2019, that a team of clinicians in the United States published a first management protocol for preservation of gonads in individuals with AIS.[51] We have no evidence that such protocols are being taken up in Australia.

In 2019, a clinical team in Brisbane published a review of cases managed by the Paediatric and Adolescent Gynaecology Service where, likely following age of diagnosis, 'In CAIS, bilateral gonadectomies were most often done at infancy'; all individuals with PAIS were also subjected to gonadectomies.[52]

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[48] J Pleskacova et al, 'Tumor Risk in Disorders of Sex Development' (2010) 4(4–5) *Sexual Development* 259.
[49] Michele A O'Connell et al, 'Establishing a Molecular Genetic Diagnosis in Children with Differences of Sex Development: A Clinical Approach' [2021] *Hormone Research in Paediatrics* 1 ('Establishing a Molecular Genetic Diagnosis in Children with Differences of Sex Development').
[50] Australasian Paediatric Endocrine Group et al, *Submission of the Australasian Paediatric Endocrine Group to the Senate Inquiry into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development* (Submission, 27 June 2013) <http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>.
[51] Erica M Weidler et al, 'A Management Protocol for Gonad Preservation in Patients with Androgen Insensitivity Syndrome' (2019) 32(6) *Journal of Pediatric and Adolescent Gynecology* 605.
[52] Adikari et al (n 23).

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.[53]

Historically, some women with complete AIS were excluded from competitive sport following chromosomal tests. Some women with partial AIS remain excluded. Women in such situations often have no prior knowledge of their variation, and have suffered humiliation, loss of career and, in at least one documented case, home and relationship.[54]

Chromosomal testing was abandoned as an unjust method of determining sex before the end of the twentieth century[55] before being reintroduced by World Athletics in recent years. That reintroduction of testing affects women with partial AIS and some other variations such as 17-beta hydroxysteroid dehydrogenase 3 deficiency, and 5-alpha reductase deficiency. This testing is contested, and key evidence supporting testing has been amended to remove an unsubstantiated claim of what Jeré Longman summarises as a 'causal connection between high testosterone levels and enhanced athletic performance among elite female athletes'.[56]

## 4.2 Congenital adrenal hyperplasia

Children with congenital adrenal hyperplasia (CAH) may necessitate immediate medical attention from birth to manage salt wasting. Salt wasting is potentially fatal and neonatal bloodspot screening is being introduced nationally to identify and treat children at risk.[57]

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.[58] Research to date has, however, found that a diverse range of potential factors including genetics and environmental factors, may be responsible for sexual attraction.[59] 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*

[53] For example, see Faye Kirkland, 'Intersex Patients "Routinely Lied to by Doctors"', *BBC News* (online, 22 May 2017) <http://www.bbc.com/news/health-39979186>.
[54] Maria José Martínez-Patiño, 'Personal Account A Woman Tried and Tested' [2005] *The Lancet* 366.
[55] Simpson J et al, 'Gender Verification in the Olympics' (2000) 284(12) *JAMA* 1568.
[56] Jeré Longman, 'Scientists Correct Study That Limited Some Female Runners', *The New York Times* (online, 18 August 2021) <https://www.nytimes.com/2021/08/18/sports/olympics/intersex-athletes-olympics.html>; BMJ Publishing Group Ltd and British Association of Sport and Exercise Medicine, 'Correction: Serum Androgen Levels and Their Relation to Performance in Track and Field: Mass Spectrometry Results from 2127 Observations in Male and Female Elite Athletes' (2021) 55(17) *British Journal of Sports Medicine* e7 ('Correction').
[57] Department of Health, *Newborn Bloodspot Screening Condition Assessment Summary Congenital Adrenal Hyperplasia (CAH)* (2020) <https://www.health.gov.au/sites/default/files/documents/2020/02/newborn-bloodspot-screening-condition-assessment-summary-congenital-adrenal-hyperplasia_0.pdf>.
[58] HFL Meyer-Bahlburg, 'Will Prenatal Hormone Treatment Prevent Homosexuality?' (1990) 1(4) *Journal of Child and Adolescent Psychopharmacology* 279.
[59] Christopher Richards, 'Do Your Genes Control Who You're Attracted to?' in Genetic Support Network of Victoria (ed), *Connections* (Genetic Support Network of Victoria, 2017) 6 <https://www.gsnv.org.au/media/288183/summer_2017-2018_hr_no_bleed.pdf>.

> *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.*[60]

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.*[61]

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.[62] However, their current status in New South Wales and elsewhere Australia is undocumented.

These rationales for treatment have proven controversial.[63] 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*[64]

Other governments provide no documentation about such practices.

In November 2017, an SBS Insight program on intersex heard from Professor Sonia Grover of the Royal Children's Hospital Melbourne, commenting that surgical practices today are better than they used to be, evading questions about medical necessity and the pre-empting of personal consent.[65] Most research, as in Victoria, occurs with clinicians studying the outcomes they are interested in, on their own patients, i.e. subject to confirmation and ascertainment biases. Victorian research has presented information on 'vibration' tests on adolescents and adults, and patient views, in an attempt to justify early interventions, while also reporting separately on adverse urinary issues.[66]

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[60] Saroj Nimkarn and Maria I New, 'Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency' (2010) 1192(1) *Annals of the New York Academy of Sciences* 5.
[61] Ibid.
[62] Senate of Australia Community Affairs References Committee (n 26).
[63] Alice Dreger, Ellen K Feder and Anne Tamar-Mattis, 'Prenatal Dexamethasone for Congenital Adrenal Hyperplasia: An Ethics Canary in the Modern Medical Mine' (2012) 9(3) *Journal of Bioethical Inquiry* 277 ('Prenatal Dexamethasone for Congenital Adrenal Hyperplasia').
[64] Safer Care Victoria, 'Congenital Adrenal Hyperplasia (CAH) in Neonates' (17 February 2021) <https://www.safercare.vic.gov.au/clinical-guidance/neonatal/congenital-adrenal-hyperplasia-cah-in-neonates>.
[65] *Insight 2017, Ep 31 - Intersex* (Directed by Insight SBS, November 2017) <https://www.youtube.com/watch?v=tbiSmmCuiYo&list=PLs348akkootwcPaq6GscWFDoLDCzIH4cF&t=0s&index=5>; Carpenter, 'Fixing Bodies and Shaping Narratives' (n 30).

International evidence shows that outcomes are 'not encouraging'.[67] Kalfa and others, for example, have attempted a systematic review but such a review is rendered impossible by a lack of standardised research methods.[68] In their 2024 review in the Journal of Pediatric Urology, the authors state:

> *A large study involving 1040 people from the European multicenter dsd-life study concludes that many people with a range of DSD conditions appear to be dissatisfied with their sex lives, experience a range of sexual problems and are less sexually active than the general population [30]. The results in women with CAH seemed to vary, but in general surgery had a negative effect on sexual function*[69]

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

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

> *Within the group undergoing feminization surgery, attempts are also being made to consider girls with CAH as a separate group. In a recent study reporting the long-term results of a multicenter European registry study in women with CAH, the results cannot be interpreted as encouraging [35]. One hundred and seventy-four 46, XX individuals were included. A gynecological examination was performed in 84 of whom 9.5% had a missing clitoris, 36.7% had a missing clitoral hood, 22.6% had abnormal large labia and 23.8% had small labia. In 30% of the total study population, sex life was described as poor on the basis of patient-reported outcomes, which contrasts with the positive assessment of outcomes by 97% of clinicians and which emphasizes the need to obtain the patients' perspective...The current analysis of long-term outcomes did not take into account any additional procedures needed later in life after infant surgery. However, we know that up to 50% of patients after pediatric vaginoplasty require additional procedures later in life to allow coitus.*[70]

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

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

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

[66] Morgan Carpenter, 'From Harmful Practices and Instrumentalisation, towards Legislative Protections and Community-Owned Healthcare Services: The Context and Goals of the Intersex Movement in Australia' (2024) 13(4) *Social Sciences* 191.
[67] Nicolas Kalfa et al, 'Adult Outcomes of Urinary, Sexual Functions and Fertility after Pediatric Management of Differences in Sex Development: Who Should Be Followed and How?' [2024] *Journal of Pediatric Urology* S1477513124000524 ('Adult Outcomes of Urinary, Sexual Functions and Fertility after Pediatric Management of Differences in Sex Development').
[68] Ibid.
[69] Ibid.
[70] Ibid.

*the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.*[71]

## 4.3 17-beta hydroxysteroid dehydrogenase 3 and related traits

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

> *If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed. Prenatal diagnosis is available for the kindred of affected patients if causal mutations have been characterized*[72]

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.[73]

Additionally, according to a review paper, rates of gender change in persons with 17-betahydroxysteroid dehydrogenase 3 deficiency assigned female at birth are '39–64% of cases'.[74] This means that children subjected to feminising genitoplasties may not later come to understand themselves as girls or women.

In 2006, a clinical 'consensus statement' described the risk of gonadal tumours associated with 17β-HSD3 to be 28%, a 'medium' risk, recommending that clinicians 'monitor' gonads.[75] 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'.*[76]

However, risk levels have reduced since with the effect that contemporaneous clinical guidance associates gonadectomy with female sex assignment and not gonadal tumour risks, as stated in material associated with the relevant World Health Organization ICD-11 classification,[77] and 2016 clinical "consensus" statements.[78]

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[71] Peter A Lee et al, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care' (2016) 85(3) *Hormone Research in Paediatrics* 158 ('Global Disorders of Sex Development Update since 2006').
[72] Morgan Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (2018) 20(2) *Health and Human Rights* 205; World Health Organization, '46,XY Disorder of Sex Development Due to 17-Beta-Hydroxysteroid Dehydrogenase 3 Deficiency' in *ICD-11 Foundation* (2022) <https://icd.who.int/dev11/f/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f887793448>.
[73] Australasian Paediatric Endocrine Group et al (n 50).
[74] Peggy T Cohen-Kettenis, 'Gender Change in 46,XY Persons with 5α-Reductase-2 Deficiency and 17β-Hydroxysteroid Dehydrogenase-3 Deficiency' (2005) 34(4) *Archives of Sexual Behavior* 399.
[75] IA Hughes et al, 'Consensus Statement on Management of Intersex Disorders' (2006) 91 *Archives of Disease in Childhood* 554.
[76] Amnesty International, 'First, Do No Harm: Ensuring the Rights of Children Born Intersex.' (May 2017) <https://www.amnesty.org/en/latest/campaigns/2017/05/intersex-rights/> ('First, Do No Harm').
[77] Carpenter, 'Intersex Variations, Human Rights, and the International Classification of Diseases' (n 72); World Health Organization (n 72).
[78] Lee et al (n 71).

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

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

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

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

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

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

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

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

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

This statement is quite extraordinary. This was a clitorectomy and labioplasty (at [16]), which may sometimes be termed a 'genitoplasty' or 'vulvoplasty'. Australia, in common with many other countries, maintains a legal prohibition on Female Genital Mutilation (FGM). FGM refers to all procedures involving partial or total removal of the external female genitalia or other injury to the

female genital organs for 'non-medical reasons'.[79] In societies where female genital mutilation is a norm, it is recognised to be carried out to, inter alia, enable a woman to fully participate in society, prepare for adulthood, and meet cultural standards for female appearance.

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

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

## 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.[80] 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;[81] this 2015 clinical review states that 90% of people with Klinefelter syndrome are diagnosed after age 15, and only a quarter of individuals expected to have this variation are ever diagnosed.

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

Not all people with XXY sex chromosomes are male[82] 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.[83] Alex had received a birth certificate from Victoria stating 'indeterminate – also known as intersex'. Julie Butler, writing for Western Australian, stated:

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[79] World Health Organization et al (eds), *Eliminating Female Genital Mutilation: An Interagency Statement* (World Health Organization, 2008) ('*Eliminating Female Genital Mutilation*').
[80] Anne Skakkebæk, Mikkel Wallentin and Claus H Gravholt, 'Neuropsychology and Socioeconomic Aspects of Klinefelter Syndrome: New Developments' (2015) 22(3) *Current Opinion in Endocrinology & Diabetes and Obesity* 209 ('Neuropsychology and Socioeconomic Aspects of Klinefelter Syndrome').
[81] Ibid.
[82] S Röttger et al, 'An SRY-Negative 47,XXY Mother and Daughter' (2000) 91 *Cytogenetics and Cell Genetics* 204.
[83] Julie Butler, 'X Marks the Spot for Intersex Alex', *The West Australian* (Perth, Western Australia, 11 January 2003).

> *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.*[84]

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

## 4.5 46,X0/Turner syndrome

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

Turner syndrome is associated in the literature with significantly increased risk of heart disorders, such as aortic dissection, and has been associated with evidence of reduced life expectancy.[85] Early literature finding significantly increased risks of gonadal cancer have been challenged, and it is now more common for surgical removal to be confined to cases of mosaic Turner women with streak ovaries. Lifetime estrogen therapy is commonly prescribed for Turner women. Turner syndrome women can expect early hearing loss and may suffer the psycho-social side-effects associated with hearing loss.

[84] Ibid.

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