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Submission to the inquiry on universal access to reproductive healthcare

By Intersex Human Rights Australia (IHRA)



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2 Introduction

Thank you for the opportunity to respond to terms of reference that call for evidence on experiences of accessing sexual and reproductive healthcare by people with innate variations of sex characteristics.

A pattern of human rights abuses on infants, children and adolescents with innate variations of sex characteristics persists in Australia. These abuses are often the product of stigma, and they provoke shame and suffering. They can occur with public funding and governmental imprimatur, despite rhetoric by Australian governments that asserts the equality and dignity of LGBTI (lesbian, gay, bisexual, transgender, intersex) people, and recognition and valuing of people with intersex variations, and despite opposition by intersex community organisations, human rights institutions, and mental health professional organisations (Carpenter 2022).

In relation to sexual and reproductive health:

- our reproductive capacity is frequently disregarded and eliminated in medical interventions intended to make our appearance and function fit medical norms for female or male bodies
- these often take place before we have age and agency to express our own values and preferences
- sexual function and sensation are devalued and deprioritised in favour of appearance and conformity to social and cultural stereotypes
- our access to reproductive services is impeded
- our lives are frequently not seen as worth living, impacting on the reproductive choices of potential parents

Social attitudes, such as body shaming, and ideas about how our bodies should look and function, play a key role in determining how we are treated, and even if we are born.

In general, infertility is a huge problem for our community. To a significant degree, infertility is a problem for many of us specifically because of the way we have been treated by medicine. Whether infertility or impaired fertility are iatrogenic or inherent, we all deserve the right to access reproductive and sexual services, free of shame and stigma.

Just as sex selection is a cause for concern for women, so selection on the basis of sex characteristics is a concern for the intersex movement.

We seek specific attention to our health and human rights concerns.

2.1 About this submission

Intersex Human Rights Australia (IHRA) is a national charitable organisation run by and for people with innate variations of sex characteristics. We were formerly known as Organisation Intersex International Australia (OII Australia).

We registered as a not-for-profit company in 2010 and became a charity in 2012. Since December 2016 we have been funded by foreign philanthropy to employ two part-time staff to engage in policy development and systemic advocacy work.

We promote the health and human rights of people with innate variations of sex characteristics, including rights to bodily autonomy and self-determination. Our goals are to help create a society where intersex bodies are not stigmatised, and where our rights as people are recognised. We build community, evidence, capacity, and provide education and information resources. Our staff and directors engage in work promoting consistent legislative and regulatory reform, reform to clinical practices, improvements to data collection and research. We also work to grow the intersex movement and the available pool of advocates and peer support workers, and address stigma, misconceptions and discrimination.

Our work is conducted in line with a 2017 community-designed platform, the *Darlington Statement*, which sets out priorities for the intersex movement in our region (AIS Support Group Australia et al. 2017). Together with Intersex Peer Support Australia (IPSA, also known as the AIS Support Group Australia) we comprise the Darlington Consortium.

2.2 Authorship

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

Morgan Carpenter is a graduate in bioethics at the University of Sydney School of Medicine. He wrote our submissions to Senate inquiries on anti-discrimination legislation, and involuntary or coerced sterilisation, and also participated in hearings on those inquiries. He participated in the first intersex expert meeting, organised by the UN (Office of the High Commissioner for Human Rights 2019). He was an expert and drafting committee member for the *Yogyakarta Principles plus 10* (Yogyakarta Principles 2017) and a member of an Australian Human Rights Commission expert group on protecting the human rights of people born with variations of sex characteristics in the context of medical interventions (Australian Human Rights Commission 2021). Carpenter has consulted or been a reference group member for the UN Office of the High Commissioner for Human Rights, the World Health Organization, the ACT government, Australian Bureau of Statistics, NSW Health, and other bodies. His doctorate studies in bioethics at the University of Sydney School of Public Health focus on epistemic injustice, medicine, law and the human rights of people with innate variations of sex characteristics.

Some information in this submission is drawn from a 2021 report by Morgan Carpenter written to inform the Australian Institute of Health and Welfare (Carpenter 2022).

3 Recommendations

We recommend to the Committee that the Commonwealth government:

1. Implement clear national legislation to protect the human rights of people with innate variations of sex characteristics in medical settings, taking account of an approach expressed in draft legislation developed by the Australian Capital Territory.
2. In the alternative, ensure implementation of nationally consistent legislation to protect people with innate variations of sex characteristics in medical settings, taking account of an approach expressed in draft legislation developed by the Australian Capital Territory.
3. Implement revisions to model law on female genital mutilation to ensure that such legislation does not continue to provide legal loopholes permitting forced and coercive surgeries on children with innate variations of sex characteristics.
4. Address stigma and discrimination contributing to genetic selection and prenatal terminations on grounds of sex and sex characteristics.
5. Recognising the need for a legislative protections as a prerequisite, provide for national human rights-affirming standards of care for medical treatment involving people with innate variations of sex characteristics.
6. Reform paediatric MBS item codes to end reimbursement incentives for unnecessarily early surgeries on children with innate variations of sex characteristics.
7. Ensure that people with innate variations of sex characteristics are able to access subsidised treatment for family planning purposes, including to surgically retrieve and implant sperm, eggs and tissues, on the same basis as other forms of subsidised reproductive healthcare.
8. Provide for adequate national resourcing for peer and family support and advocacy services for people with innate variations of sex characteristics and our families, including a dedicated helpline.
9. Provide for redress to persons with innate variations of sex characteristics having undergone forced and coercive medical procedures, including access to ongoing and reparative treatments.
10. Provide for medical education to increase capacity of the medical, health, family and domestic violence support workforces to provide services to people with innate variations of sex characteristics, including education on the human rights and ethical issues engaged by medical practice and stigmatisation.

4 Our population

IHRA defines people with innate variations of sex characteristics in line with a 2016 statement by human rights experts, published by the OHCHR:

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 (Office of the High Commissioner for Human Rights 2019)

We acknowledge the diversity of this population in our diagnoses, identities, legal sexes assigned at birth, genders, gender identities, and the words we use to describe our bodies. At least 40 different traits or variations are known (Hiort 2013), most of which are genetically determined.

Respondents to a large Australian sociological study of people born with atypical sex characteristics in 2015 (T. Jones et al. 2016) had more than 35 different variations, including 5-alpha-reductase deficiency, complete and partial androgen insensitivity syndrome (AIS), 45,X0 (Turner's syndrome or TS), 47,XXY (Klinefelter syndrome), bladder exstrophy, clitoromegaly, congenital adrenal hyperplasia (CAH), cryptorchidism, epispadias, Fraser syndrome, gonadal dysgenesis (including Swyer syndrome), hyperandrogenism, hypospadias, innate forms of hypogonadism (for example Kallmann syndrome), leydig cell hypoplasia, micropenis, mosaicism involving sex chromosomes, mullerian (duct) aplasia, mullerian agenesis and vaginal agenesis (Mayer-Rokitansky-Küster-Hauser syndrome or MRKH), ovotestes, progestin induced virilisation, XX male (De la Chapelle syndrome), Triple-X syndrome (XXX).

Clinicians frequently use a stigmatising label, 'Disorders of Sex Development' ('DSD'), to refer to many intersex variations.

IHRA has never existed 'for' people with a particular identity or sex marker. We have always recognised that the identities and experiences of people with intersex variations are diverse, and we have always sought to address misconceptions as they contribute to stigmatisation. We are here for all people with intersex traits; that is, everyone who experiences or risks stigmatisation and harm because of our innate sex characteristics.

In legislative settings, we propose use of terminology such as 'innate variations of sex characteristics' to refer to people with relevant traits, in order to facilitate legislative and regulatory protections irrespective of diagnosis, age and agency, and irrespective of assumptions regarding legal classification and identity.

5 Human rights framework and recommendations

Australia is fortunate, and unusual internationally, in having two major national inquiries that have reported on the health and human rights of people with intersex variations:

- a 2013 report by the Community Affairs References Committee on the involuntary or coerced sterilisation of intersex people, and
- a 2021 report by the Australian Human Rights Commission on ensuring the health and human rights of people born with variations of sex characteristics.

While the existence of these inquiries is an expression of the hard work of advocacy by IHRA and others, the recommendations of neither inquiry have been implemented. UN Treaty Bodies have recommended implantation of the Community Affairs References Committee recommendations. In 2017, we co-ordinated the drafting of a community declaration setting out our demands. We have also collaborated where practicable with clinical organisations.

5.1 Community Affairs References Committee report, 2013

In 2013, the Community Affairs References Committee held an inquiry into the involuntary or coerced sterilisation of people with disabilities, and of intersex people (Senate of Australia Community Affairs References Committee 2013). In its 2013 report, the Committee found that:

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

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. Those issues include reducing parental anxiety, and ensuring social awareness and acceptance of diversity such as intersex. Surgery is unlikely to be an appropriate response to these kinds of issues (Senate of Australia Community Affairs References Committee 2013)

The Committee report called for protocols and guidelines consistent with recommendations by IHRA (then named Organisation Intersex International Australia):

3.129 The proposals put forward by Organisation Intersex International have merit, and are consistent with the committee's conclusions. The committee believes that a protocol covering 'normalising' surgery should be developed, and then adhered to in all cases of intersex children. Such a guideline should be consistent with Organisational Intersex International's recommendations (Senate of Australia Community Affairs References Committee 2013)

Responding to the Senate inquiry, the federal government stated 'the substantive regulation of medical treatment is a matter for state and territory governments' (Attorney General's Department 2015). However, the federal government has played a key role in establishing a national framework for similar legislation, for example, in ensuring nationally

consistent legislation to prohibit female genital mutilation, with a review of such legislation occurring contemporaneously with the Senate inquiry (Attorney General's Department 2013).

No Australian government has implemented the Committee recommendations. Medical practices that take place too early to have regard for individuals' values and preferences have persisted unchanged, including early feminising surgeries, masculinising surgeries, and sterilisations.

5.2 Darlington Statement, 2017

The *Darlington Statement* is a community consensus statement by Australian and Aotearoa/New Zealand intersex organisations and advocates, signed in March 2017 (AIS Support Group Australia et al. 2017). The Statement informs our position. In it, we identify our core human rights concerns as including:

*5. Our rights to **bodily integrity, physical autonomy and self determination** (AIS Support Group Australia et al. 2017).*

Key relevant concerns identified in the Statement aim to address stigma, shame, a lack of oversight of medical practices and failure to respect the human rights of children in medical settings:

B. We observe that, despite the best efforts of intersex human rights defenders, discrimination, stigmatisation and human rights violations, including harmful practices in medical settings, continue to occur in Australia and Aotearoa/New Zealand.

*16. Current forms of **oversight of medical interventions** affecting people born with variations of sex characteristics have proven to be inadequate.*

a. We note a lack of transparency about diverse standards of care and practices across Australia and New Zealand for all age groups.

b. We note that the Family Court system in Australia has failed to adequately consider the human rights and autonomy of children born with variations of sex characteristics, and the repercussions of medical interventions on individuals and their families. The role of the Family Court is itself unclear. Distinctions between "therapeutic" and "non-therapeutic" interventions have failed our population. (AIS Support Group Australia et al. 2017)

In the Statement, we call for a set of interrelated reforms:

- *prohibition as a criminal act of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children [born with variations of sex characteristics] without personal consent*
- *mandatory independent access to funded counselling and peer support [i.e. resourcing of intersex-led organisations to provide peer support, systemic advocacy and services]*

- *appropriate human rights-based, lifetime, intersex standards of care with full and meaningful participation by intersex community representatives and human rights institutions*
- *independent, effective human rights-based oversight mechanism(s) to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations (AIS Support Group Australia et al. 2017)*

5.3 Relevant UN Treaty Body recommendations to Australia, 2017-9

In response to submissions by IHRA and others, the Human Rights Committee (2017), Committee on Economic, Social and Cultural Rights (2017), Committee on the Elimination of Discrimination against Women (2018), Committee on the Rights of the Child (2019) and the Committee on the Rights of Persons with Disabilities (2019) have called on the Australian government to ensure that children with intersex variations are protected from human rights abuses in medical settings, and called for access to peer support, and redress. In doing so, treaty bodies have sometimes explicitly called for implementation of recommendations of the Senate Community Affairs References Committee.

The Committee on the Elimination of Discrimination against Women and the Committee on the Rights of the Child have made recommendations that that positioned forced and coercive medical interventions on intersex children within its framework on harmful practices. Sustainable Development Goal target 5.3 refers to the elimination of harmful practices (Sustainable Development Solutions Network Undated).

In July 2018, in concluding observations to Australia, the Committee on the Elimination of Discrimination against Women (CEDAW), made the following statements:

Harmful practices

25. The Committee takes note of the State party's commitment to providing support for women who are victims of forced marriage, regardless of their cooperation with the prosecution authorities. It is concerned, however, about the following:

[...] (c) The conduct of medically unnecessary procedures on intersex infants and children before they reach an age when they are able to provide their free, prior and informed consent, as well as inadequate support and counselling for families of intersex children and inadequate remedies for victims; [...]

26. Recalling the joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child (2014) on harmful practices, the Committee recommends that the State party ensure adequate protection and support for victims of forced marriage, regardless of their collaboration with the prosecution authorities, and also recommends that the State party:

[...] (c) Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary surgical or other medical procedures on intersex children before they

reach the legal age of consent, implement the recommendations made by the Senate in 2013 on the basis of its inquiry into the involuntary or coerced sterilization of intersex persons, provide adequate counselling and support for the families of intersex children and provide redress to intersex persons having undergone such medical procedures; (Committee on the Elimination of Discrimination against Women 2018)

In September 2019, the Committee on the Rights of the Child made similar recommendations to Australia:

Harmful practices

31. The Committee welcomes the criminalization of forced marriage and taking note of target 5.3 of the Sustainable Development Goals, urges the State party to:

[...] (b) Enact legislation explicitly prohibiting coerced sterilisation or unnecessary medical or surgical treatment, guaranteeing bodily integrity and autonomy to intersex children as well as adequate support and counselling to families of intersex children. (Committee on the Rights of the Child 2019)

In 2019 the Committee on the Rights of Persons with Disabilities in document CRPD/C/AUS/CO/2-3 positioned their recommendations to Australia within its comments on Article 17, "Protecting the integrity of the person":

Protecting the integrity of the person (art. 17)

33. The Committee is seriously concerned about:

(a) Ongoing practice of forced sterilization, forced abortion and forced contraception of persons with disabilities, particularly women and girls, without their free and informed consent, which remains legal;

(b) Unregulated use of involuntary surgery on infants and children born with variations in sex characteristics, and other intrusive and irreversible medical interventions, without their informed consent or evidence of necessity.

34. The Committee urges that the State party to:

(a) Review and amend the Family Law Rules 2004 relating to Medical Procedure Applications in line with the Convention and adopt uniform legislation prohibiting, in the absence of free and informed consent, the sterilization of adults and children, the administration of contraception and abortion procedures on women and girls with disability;

(b) Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary, invasive and irreversible medical interventions, including surgical, hormonal or other medical procedures on intersex children before they reach the legal age of consent ... without their free and informed consent of the person concerned; also provide adequate counselling and support for the families of intersex children and redress to intersex persons having undergone such medical procedures. (Committee on the Rights of Persons with Disabilities 2019)

In appearances before UN Treaty Bodies, Australian government staff have sadly mistaken intersex for transgender, and have been put in the position of defending early surgeries, or acknowledging that such practices are ‘under review by the Government’ (see, for example, Stop IGM 2017; Attorney General’s Department 2018).

In the sixth periodic report submitted by Australia to the Committee (Australian Government 2019), reference is made to inquiries by the Australian Law Reform Commission (ALRC) and Australian Human Rights Commission (AHRC), which we refer to in following sections. To summarise, the ALRC report made no relevant recommendations. The AHRC report made constructive recommendations in 2021, but the government has not responded to the report.

No actions have been taken by Australian jurisdictions to ensure that infants, children, adolescents and adults are protected from such practices, except for proposals for legislative reform in the Australian Capital Territory and, at a much earlier stage, in Victoria.

There is no substantive resourcing for support for children and families, with the exception of some funding in the Australian Capital Territory and pilot or intermittent funding in Victoria and Queensland.

No provisions have been made to provide redress to individuals subject to interventions without their personal informed consent.

5.4 Australian Human Rights Commission report, 2021

In October 2021 the Australian Human Rights Commission (AHRC), made 12 recommendations in a report, *‘Ensuring health and bodily integrity’* (2021) aimed at ensuring a human rights-based approach to decision-making on medical interventions. We thank the AHRC for their work. The report builds on recommendations of the earlier Senate committee inquiry.

As anticipated, the report found that some early surgical interventions are necessary for physical health and well-being, or permissible with personal informed consent, but others are justified through appeals to gender stereotypes and medical eminence, fears of future stigmatisation, and overly loose conceptions of medical necessity and therapeutic treatment that permit these as rationales for treatment and consented to by parents or carers (Australian Human Rights Commission 2021, 44 and 74). There is no firm evidence base for current medical practices (Australian Human Rights Commission 2021, 74 and 119; Lee et al. 2016, 176).

Doctors specialising in aspects of physical health have argued that psychosocial factors and mental health are appropriate reasons for early surgical intervention. However, professional bodies of psychiatrists and psychologists have rejected these rationales because of the mental health consequences of treatment without personal consent on such fundamental aspects of people’s bodies and identities (Australian Human Rights Commission 2021, 78 and 81).

Additionally, the AHRC report found it necessary to refute a straw man argument, that some advocates want ‘a complete moratorium on all genital/gonadal surgery until the individual is able to give informed consent’ (these claims are also evident in recent Australian clinical papers, such as Vora et al. 2021; Vora and Srinivasan 2020). Citing a submission by the Australasian Paediatric Endocrine Group, the AHRC commented:

Some stakeholders seemed to base their opposition to any legal sanctions on the premise that all medical interventions modifying sex characteristics would be prohibited, in all circumstances. However, neither the Commission nor any stakeholders have advocated such a blanket prohibition (Australian Human Rights Commission 2021, 131).

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

There is real risk that, without changes to oversight mechanisms, interventions will continue to be made that are not medically necessary and which could have been deferred under a precautionary approach. Current practice has included interventions that are based on psychosocial rationales, such as gender-conforming treatments. [...] current international and Australian clinical guidance allows clinicians to take psychosocial factors, such as cultural or social pressure, into account as relevant when considering whether an intervention should be proposed. (Australian Human Rights Commission 2021, 120)

The AHRC recommendations address the following matters:

- legislative reform by Australian governments to ensure that medical interventions to ‘modify the sex characteristics of people born with variations in sex characteristics should be guided by a human rights framework’, with effective independent oversight, and with criminal penalties
- resourcing for peer support and advocacy organisations; development of new resources to increase awareness and reduce stigma, developed by community organisations with public funding
- new national guidelines, which are not intended to eliminate a need for framework legislation
- access to comprehensive care across the lifespan
- funding for community-led research and national data.

To date, only one of eight States and Territories (the Australian Capital Territory) has published draft legislation to prohibit harmful practices on children with intersex variations (Chief Minister, Treasury and Economic Development Directorate 2022a). One additional jurisdiction (Victoria) has sought advice on the form and content of possible legislation (Department of Health 2021).

The federal government has made no response to the report. As yet, it has identified no proposals for either national legislation, nor to ensure nationally consistent legislation.

No other States and Territories, nor the federal government have made formal public responses to the AHRC report recommendations. Many States and Territories, and many federal government departments, unfortunately still struggle to understand the population (Carpenter 2022).

6 Clinical position statements

6.1 Australian Medical Association

The Australian Medical Association (AMA) adopted a position statement in 2021 that states:

Being LGBTQIA+ is normal, healthy, and representative of the diversity in human sexuality, gender identity, and sex characteristics. The historical pathologisation of LGBTQIA+ people is associated with poorer health outcomes at the individual and population level (Australian Medical Association 2021)

The AMA calls on medical practitioners to:

Affirm Yogyakarta Principle 32 that “no-one should 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” (Australian Medical Association 2021)

6.2 Public Health Association of Australia

In 2021, the Public Health Association of Australia (PHAA) acknowledged that:

Infants, children, and adolescents with intersex variations remain subjected to unnecessary elective medical interventions in Australia that are understood to be human rights abuses (Public Health Association of Australia 2021)

The PHAA called on governments to ‘implement appropriate legislative reform’ to ‘end human rights abuses in medical settings’ (Public Health Association of Australia 2021).

6.3 Royal Australian and New Zealand College of Psychiatrists

In a 2018 submission to the Australian Human Rights Commission, the Royal Australian and New Zealand College of Psychiatrists stated:

The RANZCP is a strong advocate for person-centred care and is committed to improving practices that fully respect and incorporate the wishes of the individual. This is no less important for people born with variations in sex characteristics [...]

The RANZCP is concerned that sex reassignment decisions may be made within an overly narrow frame. Primum non nocere – do no harm – is central to medical ethics and carries with it powerful and longitudinal meaning for this group. Therefore, the RANZCP supports the deferral of sex assignment treatment decisions which have irreversible consequences until the person can provide informed consent, except in cases of medical necessity. [...]

While further legal consideration may be required to determine whether a legal definition of medical necessity of therapeutic treatment would be helpful, the RANZCP is concerned about the use of psychosocial rationales to justify intervention. There is little evidence for sex assignment therapies leading to positive or negative mental health outcomes. Accordingly, claims that sex assignment therapies are ‘necessary’ or ‘therapeutic’ are dubious [...] The RANZCP supports a cautious approach to decision

making where there is no physical necessity for intervention (Royal Australian and New Zealand College of Psychiatrists 2018).

The RANZCP identifies a lack of evidence for psychosocial rationales for medical interventions, leading to 'dubious' claims such interventions are therapeutic. This is explicitly stated in a 2016 clinical 'consensus' statement on treatment of children with innate variations of sex characteristics (Lee et al. 2016), and the Committee previously noted that arguments for surgery reliant on psychosocial rationales are a 'circular' argument (Senate of Australia Community Affairs References Committee 2013).

The College further stated in a 2021 position statement on LGBTIQ+ mental health:

Decisions about the medical and surgical care of intersex babies, children, adolescents, and adults should be informed by perspectives of lived experience, human rights, dignity, family and cultural perspectives, thorough informed consent, and the avoidance of unnecessary interventions. (Royal Australian and New Zealand College of Psychiatrists 2021)

6.4 Australasian Paediatric Endocrine Group

In a public submission to the 2013 Senate committee inquiry process, the Australasian Paediatric Endocrine Group (APEG), a group of paediatric endocrinologists and scientists, gave assurances of some prior change to medical practice, asserting:

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.

In the same submission, the Australasian Paediatric Endocrine Group suggested there are, presently, clear indications for surgeries:

Indications for surgery in DSD involve management of high cancer risk in the testes or ovaries, management of dysfunctional urine flow, creation of a vagina, or surgery for the purpose of appearance including reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis (Australasian Paediatric Endocrine Group et al. 2013)

Management of high cancer risks and urinary issues should not be controversial. However, these issues are intertwined with non-therapeutic rationales for treatment. In its 2013 report, the Committee was 'disturbed' by entwinement of different rationales in clinical reports (Senate of Australia Community Affairs References Committee 2013).

Regarding 'Reconstructive reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis', APEG stated:

The purpose of these procedures is for functional reasons such as to allow a male individual to urinate while standing, and for psychosocial reasons such as to allow the child to develop without the psychosocial stigma or distress which is associated with having genitalia incongruous with the sex of rearing (Australasian Paediatric Endocrine Group et al. 2013).

The term 'functional' is used inappropriately here: surgeries to ensure a man can urinate while standing are cultural, not functional, requirements for cosmetic interventions. The use of rationales explained as for psychosocial purposes by this group of non-mental health specialists is in direct opposition to the statements of mental health professionals who are qualified to assess such matters.

Subsequent to such interventions APEG notes a lack of clear evidence regarding outcomes following 'early surgical management for reasons of appearance', with:

particular concern regarding sexual function and sensation (Australasian Paediatric Endocrine Group et al. 2013)

This report thus clearly identifies how appearance is prioritised over sexual function and sensation. In a 2022 position statement, APEG makes the same claims about the harm of unspecified 'past' practices:

APEG acknowledges that some past clinical interventions led to harm, and APEG is committed to working with all stakeholders to achieve optimal outcomes in future (Hewitt et al. 2022)

No further detail is provided about which practices are acknowledged to have led to harm, when they might have ceased, or what alternative practices and procedures are now in place. The Position Statement makes no formal apology or redress, and provides no acknowledgement of the human rights of people in the care of its members.

Like previous claims about 'trends towards consideration of less' surgeries, this position is impossible to verify, and it provides no way of holding the institution or its members to account. However, our documentation of medical practices and attitudes, in the following section, shows:

- a continued commitment to early unnecessary medical interventions, including at the highest levels in clinical care
- disregard for the human rights of children and former patients
- unsubstantiated claims of reform which turn out to be unreliable or false
- no indication of any change in the prevalence of harmful practices.

7 Human rights abuses and concerns in medical settings

In this section we outline evidence relating to clinical practices that violate the human rights of people with intersex variations, including infants, children and adolescents. We have gathered evidence from multiple jurisdictions, documented in clinical publications and in other publicly available sources, such as a debate between paediatric surgeons and bioethicists including our executive director.

We outline some broad concerns with ‘surgical options’ and other cross-cutting issues such as disregard of the rights of the child. We then outline known concerns with feminising surgeries, masculinising surgeries, and sterilisation.

7.1 Sex determination and ‘surgical options’

In cases where sex determination is in doubt, Vora and Srinivasan – paediatric endocrinologists in New South Wales, Australia – stated in a 2020 article in the *Australian Journal of General Practice* that:

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

Morgan Carpenter wrote to a co-author of this paper in September 2021 in an attempt to ascertain the meaning of ‘quality of sexual function’ and query other matters, but no response has been received.

The reference to ‘quality of sexual function’ and ‘potential adult gender identity’ appear indicate an attempt to predict a more likely future gender identity and sexual role, reflecting an attempt to construct future cisgender, heterosexual adults.

The reference to ‘surgical options’ is a clear indication of the persistence of early unnecessary medical interventions to modify sex characteristics that are predetermined by sex registration. This is illustrated in statements on 17 β hydroxysteroid dehydrogenase 3 deficiency (17 β -HSD3) in the World Health Organization Foundation for the International Classification of Diseases:

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 2022)

In our view, it is perfectly acceptable for a provisional legal and social assignment of sex to occur, with neither surgical nor other medical intervention being required as a result.

This trait is ‘often misdiagnosed in infancy and detected at puberty in genetic males who have been either raised as females and develop hirsutism and primary amenorrhoea, or raised as males and have gynecomastia and incomplete male genital development’ (World Health Organization 2022). This indicates that risks or experiences of early surgeries and hormonal interventions due to gender stereotypes are not limited to situations where sex determination is considered challenging.

Implications for sexual and reproductive health include:

- Early decisions about sex of rearing do not conform to ideological perspectives that universally associate XY chromosomes with male assignment and XX chromosomes with female assignment. Instead, for people with visible differences evident at or by birth, these take account of a combination of subjective factors, assumptions about future identity, poorly evidenced information, and empirical evidence. It is harmful to rely on low quality evidence, assumptions of future identity, and subjective factors such as surgical outcomes where these pre-empt personal consent.
- In particular, assumptions about future participation in heterosexual intercourse play a significant role in decision making about assignment and treatment.
- The population impacted by these questions is small, but population size should not impede action to ensure that treatment meets fundamental human rights norms.

7.2 Equivocation about medical necessity

In the earlier cited 2020 paper by two New South Wales paediatric endocrinologists in the *Australian Journal of General Practice*, the authors equivocate about the meaning of ‘medical necessity’, and create a surprising juxtaposition between a lack of clinical consensus on surgeries, while lack of a ‘universal interpretation’ of medical necessity means that no consensus is possible regarding delay of unnecessary treatment. Both statements are taken to support unfettered clinical judgement regarding surgeries:

There is currently no consensus in relation to the need for, or optimal timing of, many surgical interventions [...]

patient advocate requests for deferral of non-therapeutic surgery, despite a lack of universal interpretation of ‘medically necessary surgery’ (Vora and Srinivasan 2020).

The paper also confirms the continuing role of ‘functionality’ (such as boys standing up to urinate) and ‘cosmetic appearance’ in considering surgeries:

Functionality, malignancy prevention and cosmetic appearance are all taken into account when considering surgical procedures (Vora and Srinivasan 2020).

Additionally, the authors present a straw man argument, that ‘Some patient groups advocate a complete moratorium on any genital/gonadal surgery until the individual is able to give informed consent’ (Vora and Srinivasan 2020).

The implications of this analysis for sexual and reproductive health includes:

- Reinforcement of our desire for legislation to set out community expectations in relation to the meaning of medical necessity in relation to interventions on children with innate variations of sex characteristics.

7.3 ‘Fixing’ children and medical experimentation, in a bioethics debate

In a recorded and publicly-viewable debate between paediatric surgeons and bioethicists in 2020, Professor John Hutson AO, chair of paediatric surgery at the University of Melbourne, described the sexual development of children with intersex traits as ‘incomplete’ and in

need of being 'fixed' (J. Hutson et al. 2020). Professor Hutson is a recipient of the Order of Australia (one of Australia's highest awards) for his services to medicine, 'particularly in the field of paediatric surgery' and a recipient of the American Academy of Pediatrics medal in Urology (Royal Children's Hospital Melbourne Undated). Professors Sonia Grover and Clare Delany, and Morgan Carpenter, also participated. Hutson, Grover and Delany are all associated with the Royal Children's Hospital, Melbourne:

Professor John Hutson: The secret is that you've got to make sure that they [parents] understand normal sexual development and the child's, the sexual development if this particular baby is incomplete. We haven't figured out yet what the real gender is. And that doesn't mean that we won't be able to and that we won't be able to fix it.

And I agree with Sonia, that the most important thing is to make them understand that they've otherwise got a completely normal baby, usually. Once they've got that in perspective, it's not so difficult for them to cope with the fact that the anatomy is not quite right.

Professor Sonia Grover: Not quite typical.

Morgan Carpenter: Can I just raise a couple of concerns here. I have just heard words about development being incomplete, about not being normal, and about "fix it". And the student's themselves have come up with this language about intersex variation being normal. So what you're saying here is something that is quite at variance with their framing of the discussion.

Professor Sonia Grover: So I think...

Morgan Carpenter: This language about being incomplete is particularly interesting. There's quite a long history of language about being incomplete or unfinished, which presupposes that clinicians can finish or complete something.

Professor Clare Delany: Sonia? Oh, sorry, John?

Professor John Hutson: And the truth is sometimes they can do that. But not always.

In this debate, Hutson's description of the bodies of children with intersex traits as 'incomplete' and to 'fix', mirror words on the harms of such practices, made by Juan E. Méndez, the then UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, in his 2013 report:

irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, 'in an attempt to fix their sex', leaving them with permanent, irreversible infertility and causing severe mental suffering (UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment 2013)

Hutson also expressed his view that he does not have regard to the rights of the child, but instead about 'fixing' children to 'help' parents:

Morgan Carpenter: I also want to raise another issue and that's that if we are talking about when we know somebody's gender. I don't think we necessarily know somebody's gender when we assign a sex of rearing. We don't know somebody's gender really until they are ready to express it themselves.

Professor John Hutson: Well, I think that from my point of view, I'm not worried about the rights of the child or moral issues when I see a baby. I'm worried about how the parents are reacting to the fact that they have found that the baby isn't what they were expecting. And my job is to try and help them come to terms with that with whatever, you know, tools are available in the medical toolkit to fix them. To help them, if they think that's what required.

And most of the time, I'm looking after children with CAH, where they have got genitalia that are not either normally female or normally male, but are looking different. And the parents are very stressed by this because it is not what they were expecting because your average parent has never heard about intersex or DSD and they are expecting it to look obviously like a boy or a girl and my problem is trying to help them come to terms with the fact that it isn't looking the way they were expecting and what are we going to do about it. (J. Hutson et al. 2020)

Professor Hutson also talked about medical experimentation, and attributed poor outcomes experienced by many advocates with intersex variations to medical experimentation on subjects unable to personally consent:

Professor John Hutson: surgery for adrenal hyperplasia has been very controversial for a very long time. And one of the reasons it is very controversial is because when it was first started, nobody knew how to do it and it is really important for the medical students to recognise that adrenal hyperplasia, as a diagnosis, a disease that we understood, the abnormality in the hormones, we have only known about it since 1953. So actually I am older than the oldest person in the world who had CAH diagnosed at birth. Because I'm born from 40s. Okay? So in what that means is that in 1950s and 1960s doctors were learning to have, or learning how to treat what they thought was an important abnormality by medical and surgical treatments. And like all learning is done by trial and error. And so lots of the surgery, lots of the medical treatment, was either not very good or was actually totally wrong because at the time they didn't actually know how to do it. So they had to learn how to do it, and there was no other way to learn than by trial and error.

So there is a whole generation of people in the world who have had surgery, often in infancy, and in retrospect it does not look very good or might be completely wrong.

But the important thing to recognise is that at the time they had the surgery it, the doctors thought it was the right thing to do. Given the amount of knowledge they had at the time.

So one of the difficulties here is that the intersex community of the world are often, are often responding to the fact that they might have had treatment on themselves in infancy or childhood that turned out to be wrong, because we didn't know at the time how to make it better.

But every day we are learning how to do it better and better, and we are never doing it for what we think is inappropriate or unethical reasons, we are always trying to do it for the most ethical and the most efficient way, but that does not mean that we are perfect. We are clearly not perfect. But we are trying to, doing it better and better.

Claims about improved surgical techniques producing better outcomes fail to address the central issues of stigma, and the purpose and necessity of medical intervention. In response, Morgan Carpenter stated:

There are some ethical principles that are not so contested. Those principles are fundamental human rights principles. And those principles talk about other things. They talk about the rights of the child. They talk about the right to bodily integrity. The right to physical autonomy. And they also talk about the right to freedom from experimentation. Because children, while saving children's lives is a really fundamental imperative of medicine, this narrative about scientific progress and about how surgeries were not right, that is not a process... Children are not your objects to experiment on to get surgery right. When surgery is elective, where surgery is about what is cosmetic, that is not acceptable, that is not a good balance of rights (J. Hutson et al. 2020).

These descriptions of people with intersex variations are prejudicial, and indicative of clinical support for harmful practices at the highest levels of medicine. There has been no apology or redress for unnecessary and harmful medical interventions; these persist on infants and children before they have age and agency to express their values and preferences.

A review of '31 parent–clinician interactions in three clinics of disorders of sex development' in the US found that information provision by clinicians was motivated to produce particular kinds of treatment decision. The authors remark that:

Due to their epistemic advantages and the presentation of surgery as a solution, clinicians boost their professional authority by strategically deploying uncertainties to steer the decision-making process (Timmermans et al. 2018).

As a result, parents are not adequately or appropriately informed before making decisions about medical treatment.

The implications for sexual and reproductive health include:

- A lack of redress for individuals subjected to 'experimental' surgeries, with implications for access to reparative and ongoing treatments to mitigate consequences.
- An inability to ascertain outcomes of current medical practices, as outcomes of paediatric surgery in adults and adolescents can always be described as reflecting of obsolete practices. This results in an impaired ability to hold medical practitioners to account for current practices.
- There is consensus in legal and human rights domains regarding the human rights engaged by medical treatment but these perspectives are disregarded by front line clinicians.

7.4 Feminising surgeries, ‘genital enhancement’ and the recent MBS review

These include early genitoplasties, clitoral reductions, vaginoplasties and labioplasties, intended to make genital appearance and function fit gender stereotypes for female bodies. Publicly reimbursable medical procedures include the following paediatric-only codes, unavailable to adults who are able to personally consent to treatment:

- 37845 Congenital disorder of sexual differentiation with urogenital sinus, external genitoplasty with or without endoscopy
- 37848 Congenital disorder of sexual differentiation with urogenital sinus, external genitoplasty with endoscopy and vaginoplasty
- 37851 Congenital disorder of sexual differentiation, vaginoplasty for, with or without endoscopy (Carpenter 2022)

In a media report on feminising surgeries in 2013, the Royal Children’s Hospital Melbourne, Victoria, is reported to perform ‘10-15 genital reconstruction operations a year often on girls under the age of two’, described as ‘gender assignment or genital enhancement operations’ (Bock 2013). In the same year, the hospital reported to the Senate an ‘opinion’ favouring early surgeries (Royal Children’s Hospital Melbourne 2013, 7).

The description of early genital surgeries on ‘girls under the age of two’ as ‘genital enhancement operations’ is particularly abhorrent.

It should be noted that numbers of procedures are difficult to quantify: reimbursements from the public purse appear to be made in only a subset of procedures, with evidence published in 2018 showing a poor fit between hospital data and national MBS reimbursement numbers (Carpenter 2018b). In particular, there appears to be no clear correlation between these surgery numbers at a single hospital and contemporaneous data on numbers of relevant surgeries appearing in Medicare data, nor a federal Department of Health review of vulvoplasties that refers to ‘congenital malformations’ associated with intersex-specific ICD codes (Carpenter 2018b, 468–74).

In analysis of data and policy prepared for the Australian Institute of Health and Welfare, Morgan Carpenter comments on troubling statements by the Medicare Benefits Schedule Review Taskforce. Changes to the language from ‘ambiguous genitalia’ and named traits to ‘congenital disorder of sexual differentiation’ misrepresented and disregarded community concerns:

the Taskforce framed this change as a ‘modernisation’ where previous ‘language used does not reflect contemporary community attitudes’ and commented that ‘medical and representative organisations were concerned that the language might be influencing non-evidence based treatment for patients’; the new terminology might ‘promote a more evidence-based approach to medical/surgical decisions’ (Medicare Benefits Schedule Review Taskforce 2019, 15 and 30). However, the statement regarding ‘contemporary community attitudes’ in relation to nomenclature disregarded and misrepresents community attitudes towards that nomenclature. Further, it chooses to disregard long-stated community and human rights institutions’ concerns regarding inadequate evidence, lack of consensus regarding necessity, and inappropriate rationales for surgery and hormone treatments ... As a process this is

troubling: clinicians in the field participated in the expert reference group for the AHRC inquiry (Carpenter 2022)

The lack of direct analogues for adults means that surgeries on children are incentivised, while the Taskforce report authors make a remark about identity that we perceive, in the circumstances, as cynical:

No directly comparable item codes exist for non-paediatric populations, while a single adult code exists for 'reconstruction' (Department of Health 2021a). The codes exist to facilitate surgeries on individuals too young to personally consent but limit access to support in adulthood. 'Patients with DSD remain free to choose their social identity', the report states (Medicare Benefits Schedule Review Taskforce 2019, 15), but not their own treatment or its timing (Carpenter 2022).

Clinical studies are scarce, lack replication, and rely on small samples and case studies that are subject to ascertainment bias and confirmation bias, for example, where staff at a paediatric hospital study their own patients in line with their own beliefs, values and preferences.

Australian evidence supporting current medical practices relies on a small single-centre study of 'long-term psychological, sexual and social outcomes' by clinicians at the Murdoch Children's Research Institute and Royal Children's Hospital of 50 of their patients (Warne et al. 2005). There is no evidence (or community knowledge) of community input into study design. The study appears intended to justify the centre's treatment model, with the clinicians reporting:

Most patients with intersex had positive psychosocial and psychosexual outcomes, although some problems were reported with sexual activity. These results overall suggest that a model of care including early genital surgery carried out at a centre of excellence with a multidisciplinary team can minimize long-term complication rates (Warne et al. 2005).

In 2020, this same small study by clinicians studying their own patients according to their own interests and paradigms is still relied upon as a justification for early surgery:

As all the participants in this follow-up study had genital reconstructive surgery in infancy or early childhood, the results did not support a change in this practice (J. Hutson 2020).

Writing in 2020, the clinicians also note significant concerns:

The DSD patients were less likely to experience orgasm and tended to experience more pain during intercourse, and they also had more difficulties with penetration than the combined control groups. In addition, they were also more likely to have less frequent sexual activity than the control groups (J. Hutson 2020).

Respondents 'reported lower self-esteem and higher anxiety traits' than controls, but had a 'generally positive psychosocial and psychosexual outcome which is in contrast to many other studies' (J. Hutson 2020). The report on this study appealed to surgical expertise at the centre as a factor in explaining outcomes perceived as good and supportive of surgical practices.

However, a systemic review by an independent team at an institute for psychiatry in Hamburg, Germany reported on the same study differently, indicated significant psychological distress in the study population:

In the study by Warne et al. (2005), the persons with DSD were similarly as distressed as a comparison group of chronic somatically ill persons. Even though the rates of psychological distress are not directly comparable to our measures, the results similarly indicate markedly increased distress in persons with DSD. (For comparison, German prevalence rates of significant psychological distress in chronically somatic ill persons range from 43% to 50%, see Harter, 2000). (Schützmann et al. 2009).

In relation to the German team's overall findings, the authors comment on the scale of adverse psychological outcomes:

Our results suggest that adults with DSD are markedly psychologically distressed with rates of suicidal tendencies and self-harming behavior on a level comparable to non-DSD women with a history of physical or sexual abuse (Schützmann et al. 2009).

Beliefs underpinning medical interventions lack evidence and clear indications, and the Victorian research is not recognised to be of high quality. For example, reflecting an earlier 2006 statement, a 2016 global clinical review states:

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 ... 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).

In 2017, the Committee on Bioethics of the Council of Europe reported that no clinically-accepted standard of care:

has emerged to explain, as a matter of science, how infant surgery will be certain to coincide with the child's actual identity, sexual interests, and desires for bodily appearance (Zillén, Garland, and Slokenberga 2017)

Safer Care Victoria, an agency of the State government charged with healthcare safety and improvement, omits consideration of human rights concerns and is inappropriately suggestive of a variety of acceptable perspectives, in a statement that normalises early elective surgeries in relation to infants with congenital adrenal hyperplasia, and gives them governmental approval:

Most surgical correction [sic] is now delayed until 6 months of age or later. Opinion currently varies between centres as to surgical management options (Safer Care Victoria 2021)

Victorian clinical reports have also identified 'increased probability of incontinence, urgency, and frequency' in a population of women with congenital adrenal hyperplasia, in comparison to a control group (Carpenter and Organisation Intersex International Australia 2015); information on these risks may not be evident to individuals who have experienced such interventions. In such research there appears to be no outcome that would suspend such medical interventions, only outcomes that necessitate further research.

The implications for sexual and reproductive health include:

- Many individuals subjected to feminising surgeries have undergone irreversible procedures that do not fit their own values and preferences, including preferences for prioritisation of sexual sensation over appearance, and preferences for different kinds of sexual practices, and expression of different identities.
- Experiences by members of our community include an inability to orgasm due to the impact of surgical interventions on sensation, and pain arising from surgeries to fold or otherwise 'hide' or 'relocate' clitoral tissue that was believed to be 'excessive'.
- Clinical and social use of the term intersex to refer to a social identity rather than an experience of physical difference can impede access to community and peer support.
- All surgeries that are not necessary for physical health and wellbeing – including so-called 'genital enhancement' and 'surgical correction' – should be delayed until individuals are old enough to freely express their values and preferences.
- Psychosocial rationales are better addressed through independent psychosocial support for parents and families, and efforts to promote the acceptance of bodily diversity. Recommendations by the Committee and the AHRC aimed at improving and resourcing psychosocial support have not been implemented.
- Anonymised information on numbers of procedures and their rationales is scattered across multiple different sources such as reimbursement data, journal articles and clinical reports. It is not comprehensive, and is not clearly and easily available.

7.5 'Appropriate urination' and masculinising surgeries

Many forms of masculinising intervention take place on children who receive a diagnosis of hypospadias. This diagnosis leads to routine early surgeries, described in a submission to the Committee by APEG in 2013, which are intended to reposition the urethra at the end of the penis for 'functional' reasons (Australasian Paediatric Endocrine Group et al. 2013).

Hypospadias is sometimes not associated with the umbrella term 'disorders of sex development' but sometimes, as in the APEG submission, it is included. To us, decisions about its inclusion or exclusion seem to be political reasons, including avoidance of controversy associated with feminising surgeries, perceptions of male vulnerability or insecurity, and a desire to continue early surgeries. Nevertheless, people with hypospadias are fully part of our community, and their treatment engages precisely the same human rights concerns.

As described by APEG, boys who appear unable to urinate standing up may undergo multiple surgeries to ensure they are able to urinate 'appropriately' (McLennan 2021). This presentation of 'appropriateness' of urination standing up indicates that treatment is being framed as 'functional', rather than 'cosmetic' or 'cultural'. In our view, this is a misuse of the term 'functional' to describe a rationale based on a cultural norm and a gender stereotype.

Related surgeries include 'hypospadias repair', while related interventions include abhorrent 'erection tests' on pre-pubertal children. Statistically, most interventions appear

to take place on children. Relevant publicly-reimbursable procedures include:

- 37815 Hypospadias, examination under anaesthesia with erection test
- 37816 Hypospadias, examination under anaesthesia with erection test, on a person under 10 years of age
- 37822 Hypospadias, distal, 1 stage repair, on a person under 10 years of age
- 37824 Hypospadias, proximal, 1 stage repair
- 37825 Hypospadias, proximal, 1 stage repair, on a person under 10 years of age
- 37827 Hypospadias, staged repair, first stage
- 37828 Hypospadias, staged repair, first stage, on a person, 10 years of age or over
- 37830 Hypospadias, staged repair, second stage
- 37831 Hypospadias, staged repair, second stage, on a person under 10 years of age.
- 37833 Hypospadias, repair of urethral fistula
- 37834 Hypospadias, repair of urethral fistula, on a person under 10 years of age (Carpenter 2022).

High numbers of masculinising surgeries take place each year in Australia, including hundreds of second or repeat surgeries and, in a sample year, more than a hundred 'erection tests' on children younger than 10 years of age (Carpenter 2022). We find this to be a disturbing practice.

In a 2020 book, John Hutson and other clinicians at Royal Children's Hospital Melbourne reported on outcomes of their early masculinising surgeries at that hospital. Hutson asserts improved psychological well-being in boys after early surgery as the primary rationale for early surgical intervention – 'no serious psychological disturbance and no memory of the intervention' (J. Hutson 2020, 311) – accompanied by a claim of surgical expertise (J. Hutson 2020). The evidence supporting these assertions was a survey of 55 minors aged 13-15 with a low response rate (B. Jones et al. 2009). The study population was too young to be able to ascertain outcomes. Lacking memory of a procedure is not an appropriate rationale for early treatment, and it pre-empts the right of any person to exercise personal autonomy regarding medical treatment.

When hypospadias repair procedures go wrong, which is known in a significant proportion of cases, the outcomes can be catastrophic. Articles in the *Journal of Pediatric Urology*, official journal of the Asia Pacific Association of Paediatric Urologists, still refer to children in situations of such iatrogenic harm as 'hypospadias cripples' (Neheman et al. 2020).

Clinical papers have identified that long-term outcomes of hypospadias repairs include urethral strictures (a narrowing of the urethra) which may not be evident until adulthood. In relation to these surgeries, Katrina Roen notes 'questionable decision-making and consent processes (Roen & Hegarty, 2018) and surgical outcomes that urologists themselves find questionable (Long & Canning, 2016; Long et al., 2017)' (Roen 2019). Non-surgical pathways are lacking (Liao, Wood, and Creighton 2015; Roen 2019).

Swedish research published in 2017 found a '40% increased probability of receiving a disability pension' in a cohort of '4378 men diagnosed with hypospadias, born between 1969 and 1993 in Sweden' (Skarin Nordenvall et al. 2017). This risk appeared evident across

subgroups, such that ‘men with hypospadias were at an increased risk of receiving a disability pension, regardless of the hypospadias phenotype’ but this appeared particularly evident in people with proximal hypospadias and those with distal hypospadias and additional diagnoses, including autism, ADHD and intellectual disabilities. It appears that all men had been subjected to surgical interventions (it was ‘unlikely that any patient with hypospadias who required surgery were not included’). The authors could not ‘rule out that some men’s work capacity has been severely impaired due to repeated hypospadias surgeries’.

Small penis size and atypical functionality provoke significant social stigma. As previously identified by this Committee, it is not evident that surgery is capable of providing any kind of solution to such stigma (Senate of Australia Community Affairs References Committee 2013).

Other kinds of masculinising medical intervention include mastectomies and hormone treatment. Breast development in men can be more often physically evident than physical diversity affecting genitals and gonads. It is subject to significant social stigma and partial subsidisation of surgical treatment is possible. Inherently, such surgeries and hormone treatment affect adolescents and adults, and personal informed consent should be a prerequisite.

In our view, surgical interventions based on rationales that do not reflect urgent medical necessity should only occur when they reflect personal values and preferences, and are based on access to high quality information not motivated to produce any specific treatment outcome. However, each of these factors can be distorted by stigmatisation. We discuss hormone treatment later in this submission.

The implications for sexual and reproductive health include:

- Many individuals subjected to masculinising surgeries have undergone irreversible procedures that do not fit their own values and preferences, including preferences for prioritisation of sexual sensation over appearance, prioritisation of sexual sensation over social conformity in physical appearance, and preferences for different kinds of sexual practices, and expression of different identities.
- Experiences by members of our community include a reliance on the regular insertion of devices (‘sounds’) into the urethra in order to maintain an ability to urinate.
- People with innate variations of sex characteristics benefit from more realistic understandings of human diversity and acceptance of many different body types, physical appearances and ways of being.

7.6 Erroneous claims of changed practices

In 2012 the Department of Communities in Queensland had asserted:

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

This assertion makes all the more remarkable and profoundly disturbing comments by a Family Court judge in a case adjudicated in 2016. The case, *Re Carla (Medical procedure)*, adjudicated in Brisbane, may have been instrumental in instigating an inquiry on protecting the human rights of people born with variations of sex characteristics in medical settings by the AHRC. An anonymous 'relevant' government department appeared as a friend of the Court.

The case involved a pre-school child with 17 β hydroxysteroid dehydrogenase 3 deficiency, described by the judge as a 'sexual development disorder'. The judge stated that the child had already had surgeries that 'enhanced the appearance of her female genitalia', without recourse to the court but indicating a prior investment in a particular future appearance and identity in a preschool child (Family Court of Australia 2016, para. 2; Carpenter 2018a; Australian Human Rights Commission 2021). This statement regarding the purpose of cosmetic surgeries is abhorrent, and makes previous State government assertions regarding irreversible procedures profoundly troubling.

The case was taken to remove the child's gonads, and the judge determined that parents could authorise this treatment (Family Court of Australia 2016, para. 19; Carpenter 2018a; Australian Human Rights Commission 2021).

In 2019, a clinical team in Brisbane published a 'review of adolescent females ages 8 to 18 years of age with DSDs' managed by the Paediatric and Adolescent Gynaecology Service 'over the last 10 years' (Adikari et al. 2019). This period overlaps with both the Senate inquiry of 2013 and the AHRC inquiry that commenced in 2018. The review states that:

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

In relation to all five instances reporting regarding children with partial androgen insensitivity, the paper stated:

'Gonadectomy and feminizing genitoplasty 1 year age.'

'Gonadectomy and reconstructive surgery as infant.'

'Gonadectomy and surgical creation neovagina as child.'

'Gonadectomy and feminizing surgery age 2yo.'

'Bilateral gonadectomy.' (Adikari et al. 2019).

Feminising genital surgeries were also reported in cases involving an adolescent with 5-alpha reductase deficiency and an infant with mixed gonadal dysgenesis. No information was disclosed in relation to treatment of children with congenital adrenal hyperplasia seen at this clinic, but we anticipate that feminising genital surgeries were routine.

In cases where genitoplasties occurred during later childhood or adolescence, it is plausible that diagnosis and referral occurred later.

These procedures also can be contrasted with a previous statement by the Queensland government that asserted they do not occur (Department of Communities 2012).

The implications for sexual and reproductive health include:

- Our profound concern about reliance on poorly evidenced and erroneous statements about change to clinical practices, to promote inaction on fundamental human rights concerns.

7.7 Genital ‘enhancement’ on people with androgen metabolisation traits

Infants with 17-beta hydroxysteroid dehydrogenase 3 (17 β -HSD3) and 5-alpha reductase deficiency 2 (5 α -RD2) 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 Foundation for the International Classification of Diseases 11 suggests that gender assignment be made based on a doctor’s subjective assessment of the technical results of masculinising genital surgeries, and that genital surgeries must occur early. Elimination via selective embryo implantation during IVF is also stated as possible. The following statement is from the description for 17 β -HSD3:

If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed. Prenatal diagnosis is available for the kindred of affected patients if causal mutations have been characterized (Carpenter 2018a; World Health Organization 2022).

The Australasian Paediatric Endocrine Group (APEG) acknowledges such interventions, even while advising the Committee in 2013 that such early interventions are controversial and known to be associated with ‘particular concern’ regarding post-surgical sexual function and sensation (Australasian Paediatric Endocrine Group et al. 2013).

Additionally, according to a review paper, rates of gender change in persons with 17-beta-hydroxysteroid dehydrogenase 3 deficiency assigned female at birth are ‘39–64% of cases’ (Cohen-Kettenis 2005). This means that children subjected to feminising genitoplasties may not later come to understand themselves as girls or women.

In 2006, a clinical ‘consensus statement’ described the risk of gonadal tumours associated with 17 β -HSD3 to be 28%, a ‘medium’ risk, recommending that clinicians ‘monitor’ gonads (Hughes et al. 2006). A more recent clinical review published in 2010 reduced risk levels to 17% (Pleskacova et al. 2010) and a German multidisciplinary team advised Amnesty International in 2017 that, in any case, ‘cancer risk even for the high risk groups is not so high. We can monitor with ultrasound and for tumour markers’ (Amnesty International 2017).

However, like the WHO ICD-11 classification (World Health Organization 2022), current medical journal articles on this trait (for example, Lee et al. 2016) recommend gonadectomy with female gender assignment, and not on the basis of cancer risks.

In 2008, in the Family Court case *Re Lesley (Special Medical Procedure)*, a judge approved the sterilisation of a young child with 17 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 wrongly stated to be 'significant' (at [40]).

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

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

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

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

The judge also expressed, at [18], an assumption of future heterosexuality: 'Carla may also require other surgery in the future to enable her vaginal cavity to have adequate capacity for sexual intercourse'.

We note that language in this case describing genital ‘enhancement’ also appears in a news report on medical interventions at a Melbourne hospital (Bock 2013).

The implications for sexual and reproductive health include:

- The inappropriate use of gender stereotypes to justify irreversible surgical interventions on preschool children.
- The use of claims of genital ‘enhancement’ surgeries on young children appears in reports from Queensland and Victoria, and should never have been considered acceptable.
- Claims of an inability to monitor gonads despite calls in a 2006 clinical ‘consensus’ statement to monitor gonads, and a lack of attention to accurate, up-to-date evidence on cancer risks.
- A deliberate pre-empting of the right of people to make their own decisions, in their own time, in line with their own values and preferences.
- Inability of the courts to hold physicians to account.
- A disregard for the rights of the child and comprise a form of abuse and ill-treatment that occurs with the imprimatur of governmental institutions, and often with public funding.

7.8 Cancer risks and sterilisation of people with androgen resistance

Any individual subject to sterilising surgeries requires a lifetime of medical treatment to ensure physical and psychological health, such as access to hormone replacement therapies. These impact sexual and reproductive health, and are associated with regular examinations, testing and costs.

Persons with androgen resistance, or androgen insensitivity syndrome (‘AIS’) have XY sex chromosomes (typically associated with men), testes (typically intra-abdominal), and a phenotype or physical appearance that may vary. The majority of people with complete AIS appear to be cisgender women and a high proportion are heterosexual (Warren 2017). People with partial AIS grow up to understand themselves in diverse ways, including many women and girls with a largely typical female phenotype, and people who look and understand themselves in different ways.

Diagnosis may take place at any point during infancy or childhood (for example, if testes are mistaken for herniation) or during puberty (due to lack of menstruation). The nature of androgen insensitivity means that women with complete androgen insensitivity (‘CAIS’) will never ‘virilise’ (‘masculinise’) if their gonads are retained or if they take testosterone replacement therapy. Women and girls with partial androgen insensitivity (‘PAIS’) may experience some virilisation if their gonads are retained or if they take testosterone replacement therapy depending on the degree of insensitivity to androgens. Men and non-binary people with partial androgen insensitivity may seek virilisation to the extent this is possible. People with ‘higher grades’ of partial androgen insensitivity have limited capability for virilisation.

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

- *The complexity and diversity of cancer risk can become oversimplified, potentially elevating the perceived or communicated risk. Alternative monitoring options may be overlooked.*
- *The committee is concerned that other matters such as 'sex of rearing' or 'likelihood of gender dysphoria' are interpolated into the discussion of cancer risk. This confusion between treatment options to manage cancer risk and treatment options to manage intersex could undermine confidence in the neutrality of those advocating for surgical interventions. (Senate of Australia Community Affairs References Committee 2013)*

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

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

Our submission had remarked with concern on the following statements by Warne and Hewitt that both emphasised the highest level of risk, and associated that risk with a Y chromosome and intra-abdominal testes:

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

A Y-chromosome and intra-abdominal testes are characteristic of both people with PAIS and CAIS. Analysis that fails to distinguish between CAIS and PAIS has had the unambiguous effect of exaggerating risks for people with CAIS.

However, the risks facing people with partial androgen resistance have also been exaggerated.

Current papers suggest a low gonadal tumour risk of 0.8% associated with the gonads of people with CAIS (Pleskacova et al. 2010) while a 2021 paper by Victorian clinicians identifies significantly reduced risk levels associated with PAIS:

Malignancy risk for intra-abdominal gonads in PAIS was previously estimated at ~50%, hence prophylactic gonadectomy to mitigate this risk was recommended. More recently, data from cohorts with genetic confirmation of underlying diagnosis indicate that while the risk remains at ~30%+ for those with gonadal dysgenesis and intra-abdominal gonads, it is now estimated to be considerably lower in PAIS than previously attributed (~7% across studies where causative androgen receptor variant was genetically confirmed). (O'Connell et al. 2021, 7)

Risk levels of ~7% are comparable to or lower than risk levels associated with breast cancer in women (Queensland Health 2019).

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

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

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

We are unable to pinpoint any moment in time that divides that past from the present, and we are unaware of any Australian women with androgen insensitivity aged under 50 who have not been sterilised. In 2019, a clinical team in Brisbane published a 'review of adolescent females ages 8 to 18 years of age with DSDs' managed by the Paediatric and Adolescent Gynaecology Service 'over the last 10 years' (Adikari et al. 2019). This period overlaps with the Senate inquiry in 2013 and the AHRC inquiry.

Despite assertions to the contrary made to the 2013 Senate inquiry, all children and adolescents with androgen insensitivity reviewed were subjected to gonadectomies, typically in infancy. The authors report that:

Gonadectomy was performed in all cases, except in the Turner's variant. In [children with complete androgen insensitivity], bilateral gonadectomies were most often done at infancy (Adikari et al. 2019).

All five persons with partial androgen insensitivity were subjected to gonadectomies; in four cases, this was stated to have taken place in infancy or as a child, and associated with feminising surgeries (Adikari et al. 2019).

It was only very recently, in 2019, that a team of clinicians in the United States published a first management protocol for preservation of gonads in individuals with androgen insensitivity (Weidler et al. 2019). We have no data or evidence on whether such protocols are since being taken up in Australia.

The implications for sexual and reproductive health include:

- People with androgen resistance may have impaired fertility even where gonads are retained, but sterilisation eliminates any reproductive potential arising from novel reproductive technologies, and causes a need for lifelong hormone replacement.
- Experiences in our community include recent disclosure of a diagnosis in older adults, such that many people with AIS are and 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).
- Lack of redress and compensation for costs associated with ongoing hormonal treatment required as a result of unnecessary sterilisations based on low quality evidence and exaggerated risks.
- Ongoing impacts arising from lack of action to implement recommendations of the 2013 Committee report.

7.9 Adverse outcomes from early general anaesthetic

Large scale population studies in Australia have confirmed that exposure to general anaesthetic early in life can have adverse consequences for child development. Schneuer and others report:

Children exposed to general anesthesia before 4 years have poorer development at school entry and school performance. While the association among children with 1 hospitalization with 1 general anesthesia and no other hospitalization was attenuated, poor numeracy outcome remained (Schneuer et al. 2018).

The implications for sexual and reproductive health include:

- Children with intersex traits are unnecessarily exposed to child development risks because of the role of social stigma and gender stereotypes in justifying early surgical interventions.
- In some cases, particularly masculinising surgeries, multiple surgeries might occur in a child aged under 4, but these risks are also evident in children subjected to feminising surgeries and sterilisation.

7.10 Inappropriate hormonal treatment

The case of *Re: Kaitlin* [2017] FamCA 83, was taken by the parents of a child pseudonymously named Kaitlin. Kaitlin was born in 2000 with a pituitary impairment (Family Court of Australia 2017).

An intersex and transgender child, ‘she has not undergone stage one treatment, which comprises hormone blocking, because she suffers from hypopituitarism, in consequence of which her body is incapable of naturally producing testosterone, or indeed, many other hormones’ (at [2]). Indeed, Kaitlin ‘identified as female from a very early age. She has always resented being characterised as male’ (at [5]).

Unlike endosex (non-intersex) transgender children in Australia, where such interventions have required Family Court approval: 'At about age 12 or 13 she was prescribed testosterone in order to commence puberty' (at [6]).

This was an inappropriate intervention that failed to take account of the adolescent's own interests, values and preferences. When Kaitlin understood the nature of the hormone treatment, she was, because of her gender identity, understandably non-compliant with that testosterone treatment. Justice Tree approved 'cross-sex' hormone treatment.

In our view, Kaitlin should never have been prescribed testosterone in the first place. The adolescent child should have been consulted about her treatment, and her voice in relation to her treatment should have been respected. The Court's failure to note and comment on the failure of the parents and medical team to obtain appropriate consent to the hormone therapy instituted when Kaitlin was age 12 is unfortunate.

The implications for sexual and reproductive health include:

- Exposure to medical interventions that are not in line with personal values and preferences.
- Inability of the courts to hold physicians to account.

7.11 Access to reproductive healthcare

People with 47,XXY (Klinefelter syndrome) are clinically described as men with an extra X sex chromosome (i.e. XXY sex chromosomes, or 47,XXY). 47,XXY is associated with small testes, hypogonadism (low sex hormone levels, in this case low levels of testosterone), and also may be associated with cognitive issues such as ADHD, and a range of other health risks (Skakkebaek, Wallentin, and Gravholt 2015). As with other innate variations of sex characteristics, the innate physical characteristics of people with 47,XXY are socially stigmatised. Men with 47,XXY have poorer socioeconomic outcomes (Skakkebaek, Wallentin, and Gravholt 2015); this 2015 clinical review states that 90% of men with Klinefelter syndrome are diagnosed after age 15, and only a quarter of individuals expected to have this variation are ever diagnosed.

It is possible that persons with 47,XXY who are not diagnosed may potentially escape some stigma associated with the variation; alternatively, they may either suffer in silence, or clinical signs may be skewed towards those evident in people more likely to be diagnosed. A large study using UK Biobank data found that only 23% of individuals identified had received a prior diagnosis; individuals 'were mostly unrecognized but [47,XXY] conferred substantially higher risks for metabolic, vascular, and respiratory diseases, which were only partially explained by higher levels of body mass index, deprivation, and smoking' (Zhao et al. 2022).

Not all people with 47,XXY sex chromosomes are male (Röttger et al. 2000) but, due to the current medical paradigm that assumes all people with 47,XXY chromosomes are men, women with 47,XXY, and people who understand themselves in other ways, face additional challenges in accessing appropriate medical care, with their health and social experiences needs largely unreported.

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

However, we also seek to ensure that adolescents and youth, via approaches that facilitate supported decision-making (Intersex Human Rights Australia and Carpenter 2022), are able to freely assent or consent to treatment.

While access to reproductive services has been improved for many women, and men with viable sperm in ejaculate, access to surgical procedures to retrieve viable sperm remains inaccessible to many. We are aware of many older people with 47,XXY who have sought treatment to surgically extract viable sperm, when alternative means are not fruitful. We are aware of individuals in heterosexual relationships who have successfully utilised these methods. However, such treatments are costly, and this has proved burdensome and prohibitive for multiple community members.

These issues affecting access to reproductive services are not limited to men with sex chromosome variations: all people with innate variations of sex characteristics can find difficulty in accessing safe, knowledgeable reproductive healthcare, and MBS rebates. Social and familial expectations of girls and women to perform the role of motherhood can have a profound impact on women with innate variations of sex characteristics who find themselves unable to perform expected social roles, and this can be exacerbated by a lack of access to timely, culturally and religiously appropriate information. All of us, irrespective of diagnosis and clinical history, need access to fertility medicine. We seek positive and honest culturally appropriate discussion of potential fertility and family planning options at diagnosis to enable full and informed consideration of all options that may be available.

The implications for sexual and reproductive health include:

- People with innate variations of sex characteristics have impaired access to fertility services, including information appropriate to their physical, linguistic, cultural and religious needs.
- Different populations have distinctly different needs, including women experiencing infertility, the specific needs of men with sex chromosome variations, and the needs of people whose fertility options do not align with legal or social identity. For example, women with 47,XXY who may face a choice between services designed for women or services intended for men with 47,XXY.

7.12 Genetic selection on grounds of sex and sex characteristics

Current clinical practices indicate that clinicians may present the birth of a child with an intersex variation as an adverse outcome to be prevented. In our view, people with intersex variations are capable of living happy, fulfilling lives and such beliefs are predominantly grounded in stigmatising views about bodily diversity. The rationales for the elimination of intersex traits via genetic screening technologies frequently mirror the rationales for postnatal genital and gonadal surgeries – that is, they are grounded in the idea that it is wrong to grow up with atypical sex characteristics.

In many cases, intersex traits are considered suitable for elimination from the gene pool, and they may be offered to families and siblings of individuals with an identified intersex trait. IVF and other forms of genetic screening may eliminate sex chromosome variations. This situation is disproportionate to the impact of such traits - at odds with evidence

showing that people with innate variations of sex characteristics are capable of living happy and fulfilling lives.

Examples include:

- Androgen insensitivity, 5 α -reductase deficiency (5 α -RD2) and 17 β -hydroxysteroid dehydrogenase 3 deficiency (17 β -HSD3) can be determined via specific tests that may be proposed if siblings or family members have a relevant diagnosis. These traits appear to be considered suitable for elimination, but there are no substantive health or quality of life factors justifying elimination other than risk of forced medical interventions (for which we read risk of stigmatisation) to underpin these rationales (Carpenter 2018a). Genetic analysis that has provided welcome evidence that reduces gonadal tumour risk rates associated with partial androgen insensitivity also troublingly remarks on the value of genetic research into the origin of intersex traits for 'reproductive planning of the family' (O'Connell et al. 2021).
- In relation to people with androgen metabolism traits, the same World Health Organization information that calls for sterilisation of female-assigned children with 17-beta hydroxysteroid dehydrogenase 3 deficiency also remarks on the availability of prenatal diagnosis for kindred of affected patients (Carpenter 2018a).
- Sex chromosome variations, such as 47,XXY (Klinefelter) and 45,X0 (Turners) can be established via IVF and other tests, with high rates of terminations increasingly reported in discussions with genetics counsellors for 47,XXY. In our view, these are inconsistent with the health risks associated with the trait (Zhao et al. 2022). These traits are sometimes associated with cognitive and physical health issues, for example, 47,XXY is associated with hypogonadism and a range of other issues, but there are low overall rates of diagnosis for this variation (Gravholt et al. 2018; Herlihy et al. 2011). Sex chromosome variations are also associated with higher rates of miscarriage. Data on terminations from a range of countries shows high rates of terminations of foetuses with sex chromosome variations.
- In the case of congenital adrenal hyperplasia, prenatal treatment with dexamethasone may be offered to minimise physical expression of the trait. This treatment is controversial as it has been directly associated with consequences for the future child's behaviour and sexual orientation (Nimkarn and New 2010; Dreger, Feder, and Tamar-Mattis 2012), cognitive development (Dreger, Feder, and Tamar-Mattis 2012; Hirvikoski et al. 2012) and fertility (Poulain et al. 2012). Siblings and other family members may also be offered genetic screening. Congenital adrenal hyperplasia can be associated with salt wasting, which is potentially fatal if not treated – genital surgeries are incapable of addressing this issue.
- A 2016 Australian study reported an increase in the percentage of individuals with intersex variations receiving a genetic diagnosis from 13% to 35% (Eggers et al. 2016).
- We have identified a series of IVF providers who promote their services to LGBTI populations, while also eliminating the possibility of births of children with intersex traits, including sex chromosome variations (Carpenter 2016; Rainbow Fertility

Undated). In part this seems to be a result of identity-based misconceptions about who people with innate variations of sex characteristics are (Carpenter 2016).

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

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

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

This appeal to clinical informants is troubling, especially in the light of evidence of practices that are clearly and well-documented by clinicians in the field. For example, prior and subsequent book chapters by Amor (2012, 2020) at the Royal Children's Hospital Melbourne discuss the possibility of parents having a child with a 'DSD' as a matter of 'risk estimation', including 'risk of transmission from an affected parent to a child' or risk of having an 'affected child'. Amor omits any discussion of quality of life, and presents deselection as a value-neutral option where diagnosis of a child with a 'DSD' presents parents with 'difficult choices about future pregnancies' (Amor 2012, 2020). This framing is highly prejudicial.

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

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

Adverse impacts associated with DSD tend to draw on societal norms rather than intrinsic clinical features. This includes the experience of stigma, discrimination and other harms arising from a person's body not conforming to norms of gender or

biological sex. In particular, concerns were raised about the use of medical intervention to “fix” children born intersex without sound clinical rationale. There was also discussion of the message that inclusion of DSD in an carrier screening panel is premature, not least because of ongoing ethical debate regarding selecting against DSD. Thus, DSD that occurs in the absence of other serious clinical features did not meet our criteria for inclusion (Kirk et al. 2020).

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

The implications for sexual and reproductive health include:

- Unnecessary and unwarranted problematisation of innate variations of sex characteristics amongst siblings and family members.
- Identity-focused misconceptions about intersex people exacerbate incomprehension of potential parents who receive a clinical diagnosis.
- Reduction in birth rates of people with innate variations of sex characteristics, exacerbating societal and clinical incomprehension, and exacerbating discriminatory treatment.

7.13 Trauma, peer support and education

7.13.1 Medical trauma

Trauma arises in medical settings in numerous ways, including the following experiences, experienced as stigmatising:

- life-altering unnecessary medical interventions without personal consent
- medical examinations, typically regular and commencing from around the occasion of diagnosis
- need for ongoing medical treatment, such as hormone replacement or follow-up medical interventions; follow-up interventions are common sequelae from both feminising and masculinising surgeries, such as due to strictures or stenosis (a narrowing of the urethra or vaginal cavity)

A 2019 review of psychosocial health care practice identifies ‘clear evidence of psychosocial harm that is done through genital intervention and evidence that parents do not routinely give fully informed consent before their children undergo treatment’ while ‘genital examinations are aversive’ and the ‘very interventions intended to erase shameful differences can give rise to ongoing shaming experiences’ (Roen 2019).

In an Australian report on trauma and posttraumatic growth, Hart and Shakespeare-Finch report:

A mixed-methods sociological survey by Jones et al. (2016) of 272 intersex people in Australia provided a snapshot. [...] Reported mental health diagnoses included depression, anxiety, and post-traumatic stress disorder. Forty-two percent of participants had considered self-harm and 26% had self-harmed; 60% had experiences

of suicidal ideation and 19% had attempted suicide. These Australian findings were consistent with other reports of suicidal thoughts amongst intersex people from Europe (Schweizer et al., 2017). Conversely, one study asserted clinical psychological maladaptation did not result from being intersex and experiencing clinical violations, but rather, was the product of an interaction with other sociocultural 'risk factors' such as family structure, beliefs or problems (Sandberg et al., 2017). Nonetheless, the most consistent factor across all studies in this area was the reported benefit of intersex peer support (IPS) on positive psychological adaptation and well-being of intersex children, adolescents, adults, and family members (Jones et al., 2016; Lee et al., 2016; Sandberg et al., 2017; Schweizer et al., 2017). (Hart and Shakespeare-Finch 2021)

Access to peer and family support is a well-recognised protective factor, improving health outcomes in all situations where individuals are diagnosed or treated as having a medical disorder. In relation to people with innate variations of sex characteristics, the role of traumatic experiences in causing a lack of follow-up in clinical settings is recognised in a 2016 clinical 'consensus' statement:

The practice of withholding medical history details, along with the possibility of negative medical experiences, likely contributes to patients with DSDs frequently being 'lost to follow-up.' (Lee et al. 2016).

The same statement acknowledges the powerful role of peer support (Lee et al. 2016).

Unfortunately, peer support is not well integrated into clinical teams. A new international scoping review found that people with innate variations of sex characteristics ('VSC' in the paper) are absent and multidisciplinary teams ('MDTs') typically include only physical clinical professions:

MDTs in the literature include mainly medical professionals: endocrinologists, urologists and surgeons. The collaboration among medical professionals in MDTs lacks cooperation as one team member sets the tasks of the team while each professional works separately. Despite the importance of psycho-social support the involvement of psychologists remains secondary. The implementation of ethical principles tends to exclude people with VSC. [...] MDT tend to exclude people with VSC despite references to shared decision making processes and informed consent (Gramc, Streuli, and Clercq 2021)

This is perhaps not surprising given the composition of multidisciplinary teams, and evidence of distinctly different perspectives between peer run organisations and physical health clinicians. Indeed, not only are peer support groups absent from clinical processes, but psychosocial professionals are also rarely part of clinical multidisciplinary teams ('MDTs'). Hart and Shakespeare-Finch comment:

A survey of intersex clinical service providers showed that less than half (41%) included mental health services (Kyriakou et al., 2016). When present, Liao and Roen (2019) reported a tendency for psychologists' input to be considered optional and most valued by other MDT professionals after medical interventions had occurred. The basic criteria for informed consent was not routinely met, as evidenced through accounts of parents who elected for irreversible genital surgery on behalf of their intersex children, only to later consider if there were any other alternatives (Sanders et al., 2008). There is little

evidence to suggest clinical practices have changed; rather, clinicians continue to use clinical uncertainty around long-term outcomes of surgery, or no surgery, and ambivalent messaging about the urgency or necessity of interventions to steer decision-making along pathways preferred by clinicians (Timmermans et al., 2018). (Hart and Shakespeare-Finch 2021).

Indeed, information provision in clinical spaces can often be motivated by a desire to produce particular and contested treatment outcomes (Timmermans et al. 2018).

7.13.2 Medical, health and allied health education

A literature review of issues affecting older adults with innate variations of sex characteristics found evidence of avoidance of healthcare due to past traumatic experiences and ignorance amongst service providers, causing difficulties in finding ‘therapists capable of addressing their specific needs’ (Berry and Monro 2022).

This is corroborated by research for the NSW Health LGBTIQ+ Health Strategy. The summary of evidence for the strategy reports that people with innate variations of sex characteristics face barriers including ‘the high costs of mainstream services and the absence of intersex-sensitive mental health services in NSW’ with 72% of a small convenience sample (in a survey that coincided with the initial COVID-19 outbreak) reporting ‘that mainstream health providers are not familiar with their health needs’ while positive experiences in ‘LGBTQ-specific community health services’ related ‘to the more open and inclusive approach of LGBTQ-specific services rather than their specialisation in intersex health needs’; such specialisations do not currently exist (NSW Health 2022).

In a survey of NSW Health staff, fewer staff expressed familiarity with the needs of intersex people (19% expressing familiarity with health needs) compared to transgender and gender diverse people (30%), bisexual people and lesbians (both 43%), and gay men (51%) (NSW Health 2022).

These issues are exacerbated by the use of different frameworks to understand the population (Carpenter 2022). For example, paediatric services will use disordering language while many service providers familiar with the needs of LGBT populations publish information that is not grounded in an understanding of people with intersex traits as having diverse but recognisable bodies and that instead frames people with intersex variations as an identity group or third sex. Recent examples include:

- An easy English factsheet that describes people with innate variations of sex characteristics as a mythologised third sex, not having either a penis or a vagina (cohealth 2021), while many people with intersex traits do have either a penis or a vagina, and many of us are cisgender women and men (we recognise that some of us are gender diverse women, men or non-binary).
- A consultation report by the Meeting of Attorneys-General on national principles to address coercive control that frame LGBTIQ+ people as having a particular minority sexuality or gender identity (Meeting of Attorneys-General 2022).
- A report on the ‘voices of LGBTQIA+ young people in NSW that frames LGBTQIA+ as identities, based on a survey that entirely failed to ask for or obtain data on innate

variations of sex characteristics (Office of the Advocate for Children and Young People 2022).

7.13.3 Impacts beyond medicine and healthcare

IHRA has never existed ‘for’ people with a particular identity or sex marker, and the identities and experiences of people with intersex variations are diverse. These include impacts for health and wellbeing relating to infertility and misconceptions about people with innate variations of sex characteristics.

Hart and Shakespeare-Finch identify coping strategies such as avoidance, repression, hypervigilance and maintenance of secrecy (Hart and Shakespeare-Finch 2021). Roen calls for more and targeted education for mental health service providers (Roen 2019). Personal autonomy and psychosocial support have beneficial impacts:

Roen (2019) highlighted multiple studies which demonstrated positive parallels between increasing autonomy in decision making (informed consent) and improved psychosocial care. (Hart and Shakespeare-Finch 2021).

Impacts, however, go beyond clinical settings. For example, gender-based violence, interpersonal, domestic and family violence affect every demographic, including people with innate variations of sex characteristics. Body shaming is a particular form of abuse that impacts our population, and that (through beliefs about future stigmatisation in changing rooms and other settings) provides a rationale for early surgical interventions. Abuse and violence does not depend on disclosure or evidence of any particular identification; for example, it can be based on appearance, or knowledge of particular biological traits.

Risks of stigmatisation and harm arise beyond issues regarding physical appearance. Intersex experiences, including experiences of domestic and family violence, are often conflated with LGBTQ experiences without specific attention to the characteristics and circumstances of people with intersex variations. This framing can have adverse consequences. Framing someone as having a sexual orientation or gender identity different to the one they hold can be used to harmful effect by abusers. Assuming that intersex people are LGBTQ has obvious risks and harmful effects on non-LGBTQ intersex people. The effect of these misconceptions also means that research and surveys of LGBTIQ populations suffer from ascertainment bias and low participation rates by intersex people, and poor analysis (Carpenter 2019)

Many Australian ‘LGBTI’ domestic and family violence projects have assumed that to be intersex is to be adult, and to be non-heterosexual or non-cisgender, or a third sex (Horsley et al. 2016; Campo and Tayton 2015). Even journal articles published recently make these assumptions (for example, Asquith et al. 2019; Australian Institute of Family Studies 2020; Australian Federation of AIDS Organisations 2020). Such reports typically focus on issues of assumed personal identification, and fail to address body shaming and stigmatisation due to physical characteristics (for example, Campo and Tayton 2015).

Misconceptions about intersex as a form of personal identity have been used to harm individuals with intersex variations, including through coercive control, homophobia, transphobia and ableism directed towards individuals by their partners and family members. Anecdotally, we are aware of women with intersex variations who do not disclose their intersex variation to male partners because of the prevalence of misconceptions about

intersex. Where it occurs, disclosure to partners may rely on medical language about particular intersex variations, in an attempt to avoid such risks.

The 2013 Committee report and 2021 Australian Human Rights Commission report both recommend significant improvements to the provision of psychosocial support, including resourcing for independent peer support and advocacy organisations. With support from LGBTIQ+ Health Australia and the DSS, IHRA hopes to work to improve psychosocial support, building on a pilot project known as InterLink initiated with support from Queensland Council for LGBTI Health.¹ This work remains precarious.

7.13.4 Implications

Implications for sexual and reproductive health:

- Experiences of trauma in medical settings impair subsequent access to health services, including sexual and reproductive health services.
- Ignorance and lack of experience and expertise amongst healthcare providers, and a perceived need to train providers, impair access to health services, including sexual and reproductive health services. This can affect how people are informed about fertility options, and the ability to obtain positive and honest material about fertility and family planning options for individuals and their partners.
- A lack of resourcing for peer and family support, and the persistence of clinical practices that violate human rights, mean that peer and family support needs are difficult to quantify but lacking.
- Lack of resourcing for peer support, and broken referral arrangements, mean that many individuals lack any space to talk about their bodies and lived experiences outside of a biomedical context.
- Psychosocial support needs to be at the centre of clinical practices relating to people with innate variations of sex characteristics, not the periphery, and improvements to training and education for health providers (including mental health providers) are necessary.
- Education and awareness are also concerns for family support organisations, including those focusing on domestic and family violence, and reproductive health.

¹ See <https://ilink.net.au>

8 Legislation and guidelines

8.1 Nationally-consistent legislation

In 2019, the Australian Capital Territory (ACT) government made a welcome commitment to legislate to end harmful practices on people with intersex variations in medical settings. We commend the ACT government for this commitment, and we note that IHRA staff have been contracted work with the ACT government on aspects of related work.

In 2021 the ACT government published a listening report on responses to a key issues paper. Regarding regulation and independent oversight of medical interventions, it found that:

a prohibition would not be legally radical and would be consistent with orthodox legal thinking about child welfare (Chief Minister, Treasury and Economic Development Directorate 2021).

In 2022 the ACT government published draft legislation to protect the human rights of people with innate variations of sex characteristics in medical settings. The listening report on submissions includes the following reported statements:

Intersex and LGBTIQ+ organisations and mental health professional organisations prefer a legislated restriction on medical interventions.

Health professionals and their organisations and, some parents rejected the need for the legislation, and challenged the scope of the legislation.

Some medical professional stakeholders [had a view] arguing that psychosocial factors or 'social integration' should be valid reasons to undertake medical interventions without personal consent.

Some health professionals also argued that their work on children's health is appropriately based on social norms, while other health professionals presented an objection on the opposite grounds: they rejected the argument that intersex healthcare is influenced by social expectations about bodies (Chief Minister, Treasury and Economic Development Directorate 2022b).

In an indication of the impact of stigma and discriminatory attitudes that are not assuaged by clinical practices, reference was made by one clinician to a possibility of increased prevalence of pregnancy terminations:

A medical professional commented that the Bill may have unintended consequences on people's decision to terminate pregnancy should a variation in sex characteristics be identified prenatally. (Chief Minister, Treasury and Economic Development Directorate 2022b)

We understand that the ACT government is continuing to work towards publication of legislation to implement human rights protections for people with innate variations of sex characteristics in medical settings, and we warmly welcome this. We hope that the ACT government will provide for rights-based legislative protections for children with all innate variations of sex characteristics, irrespective of how they are characterised by clinicians.

In 2013 the federal Attorney General's Department published an analysis of nationally-consistent model law prohibiting female genital mutilation. A similar nationally-consistent legislative approach to the situation facing people with innate variations is possible, leveraging the experience of the ACT government in developing legislative proposals.

The implications for this inquiry on sexual and reproductive health include:

- A clear and regrettable gap has opened up between community, human rights and mental health bodies, on the one hand, and physical health professionals on the other, in relation to the use of social and psychosocial rationales for treatment and demands for legislative reform to ensure treatment meets human rights standards.
- We ask the Committee to call for nationally consistent legislation across Australia's states and territories, protecting all people with all innate variations of sex characteristics, building on the experience in the ACT.

8.2 National guidelines

IHRA supports national human rights affirming guidelines to ensure that medical practices meet community expectations. However, legislation is a prerequisite due to the absence of adequate evidence to support medical practices and a what a 2016 global clinical update terms 'no consensual attitude' within medicine regarding surgical practices (Lee et al. 2016, 176).

Guidelines necessarily draw on scientific and clinical evidence to construct best practice. Where guidelines exist, adherence is known to be mixed and sometimes poor. In a systemic review of barriers to clinical adherence to guidelines, Cabana et al. (1999) identify barriers including:

- knowledge, such as lack of familiarity or awareness of the guidelines or their applicability
- clinician attitudes or sentiment, including lack of agreement with specific guidelines; for example, through a different interpretation of evidence, or lack of agreement with guidelines in principle; lack of motivation or inertia; lack of belief in ability to perform a recommendation; or a lack of confidence regarding outcomes
- behavioural barriers, including patient factors such as irreconcilable characteristics or preferences
- contradictory guidelines or other issues with the guidelines
- environmental factors (Cabana et al. 1999, 1459).

Cabana et al. report that 'lack of agreement as a barrier for a specific guideline was as high as 91%' citing an example for that high range figure in the paediatric field, in a recommendation by the American Academy of Pediatrics (Cabana et al. 1999, 1460). Specific issues associated with lack of agreement include a lack of perceived credibility, and adverse responses to perceived limits on clinician autonomy (Cabana et al. 1999, 1461). While this material is dated, it forms part of recent debate in Australian hospitals (Steele 2019).

A 2018 study of clinical adherence based on quality indicators drawn from '17 common, high-burden clinical conditions' sampled medical records to evaluate the care of 6,689

children in three Australian states. It found that ‘Adherence to quality of care indicators was estimated at 59.8%’, concluding that ‘the overall prevalence of adherence to quality of care indicators for important conditions was not high’ (Braithwaite et al. 2018, 1113). The authors state that:

Adherence gaps and practice variation persist despite decades of development and endorsement of CPGs designed to promote the uptake of evidence into routine practice and to standardize care. The problems with CPGs have been well described and include redundancy, lack of currency, inconsistent structure and content, voluminous documents, and concerns about the quality of evidence on which CPGs are based (Braithwaite et al. 2018, 1122).

Similarly, a study published in 2020 of clinical adherence to guidelines relating to pregnant women with cardiac conditions in South Australia between 2003 and 2013 found ‘overall suboptimal adherence to the statewide guidelines for’ that population (Millington et al. 2020, 2).

Further, clinical guidelines are not intended to be applied universally, but instead allow for clinical judgement. For example, the authors of the South Australian study reported that ‘it is reasonable not to expect 100% concordance with the guidelines’ (Millington et al. 2020, 10), stating ‘guidelines should contain realistic and clear recommendations, which allow individual clinical judgement orientated for the patient as for efficacy versus safety’ (Millington et al. 2020, 16).

In relation to the treatment of children with innate variations of sex characteristics, clinical ‘consensus’ statements have attempted to construct consensus through an appeal to clinical eminence, given an absence of evidence.

Guidelines produced by the Intersex Society of North America in 2006 (Consortium on the Management of Disorders of Sex Development et al. 2006) that have never been clinically accepted (Zillén, Garland, and Slokenberga 2017, 42). The Consortium guidelines are dated, fail to address human rights considerations and conflicting rationales in the 2006 ‘consensus’ statement, and treat intersex people necessarily as patients (Intersex Human Rights Australia 2018, 79) yet, as stated earlier, the Committee on Bioethics of the Council of Europe found that no other protocol explains how early surgery will conform with certainty to the child’s future values and preferences (Zillén, Garland, and Slokenberga 2017, 42).

As Timmermans and others have established, clinical uncertainty and professional authority can be deployed to produce particular motivated treatment decisions where:

Professional authority thrives on clinical uncertainty because it allows clinicians to define certain issues as medical problems, suggest solutions, lean on conventional biomedical interventions (Timmermans et al. 2018).

In this context, guidelines in the absence of legislation will not effect change to clinical practice.

It is our view that legislation is a prerequisite for guidelines – necessary to set the parameters within which national guidelines can operate.

9 Legislative provisions facilitating human rights abuses in medical settings

In this section we raise concerns with legislation in multiple Australian jurisdictions that facilitates human rights abuses on children with intersex variations.

9.1 Family law and the common law definition of ‘therapeutic treatment’

The *Family Law Act 1975* (Cth) section 67ZC confers statutory authority on the Family Court (now merged into the Federal Circuit and Family Court of Australia) to make orders relating to the welfare of children and directs that in making such orders “a court must regard the best interests of the child as the paramount consideration” (Commonwealth of Australia 2018)

The legal case *Re: Marion* established a common law principle that, to be simplistic, parents can consent to most medical interventions on their children, with the exception of those deemed non-therapeutic.² The term therapeutic is not well defined and can have been determined to include ‘cosmetic deformity’. In the case *Re: Carla*, Forrest J (the judge) cited the opinion of Brennan J in *Re: Marion* at [269], where Brennan J stated:

I would define treatment (including surgery) as therapeutic when it is administered for the chief purpose of preventing, removing or ameliorating a cosmetic deformity, a pathological condition or a psychiatric disorder, provided the treatment is appropriate for and proportionate to the purpose for which it is administered. “Non-therapeutic” medical treatment is descriptive of treatment which is inappropriate or disproportionate having regard to the cosmetic deformity, pathological condition or psychiatric disorder for which the treatment is administered and of treatment which is administered chiefly for other purposes [45] (Family Court of Australia 2016)

Forrest J heard that all medical witnesses found Carla’s sterilisation to be in her best interests, and argued that this was within ‘the bounds of permissible parental authority’ (Carpenter 2017).

This interpretation of ‘therapeutic treatment’ and the best interests test have not served people with intersex variations. In particular, the best interests test has been utilised to justify early and unnecessary medical interventions. In relation to *Re: Carla*, Kelly and Smith report:

Forrest J relied on the affidavit evidence of Carla’s parents and her treating medical professionals to conclude that surgery was in Carla’s best interests. In their affidavit, Carla’s parents’ stated that ‘Carla acts as a girl’ and does not identify as ‘anything but female’. [...]

² The factors which the Court considered significant in determining which cases fall outside the scope of parental authority in *Marion’s Case* were that the procedure was non-therapeutic; invasive and irreversible; that there was a significant risk of making the wrong decision; and that the consequences of a wrong decision would be grave and serious. (*Re: Marion* [250]). While subsequent cases on the scope of the special medical jurisdiction has been debated within cases such as *Re Jamie* and *Re Kelvin*, it is clear that therapeutic status of a procedure remains a key criterion, if not necessarily conclusive of the issue.

Based on the evidence provided to him, Forrest J approved the gonadectomy, finding it to be in Carla's best interests. Forrest J also approved 'such further or other necessary and consequential procedures to give effect to the treatment of Carla'. Beyond oestrogen treatment these 'consequential procedures' are not defined and for this reason, we are of the view that it was not actually possible to determine that a range of undefined procedures planned for some time in the future, are in Carla's best interests (Kelly and Smith 2017).

Kelly and Smith argue that the treatment in Re: Carla "sets a dangerous precedent":

the medical evidence provided to the Court to justify surgery was incomplete and the reasoning and analysis concerning the therapeutic nature of the proposed surgery lacks rigour. In addition, a concerning aspect of Carla's earlier medical care (undertaken prior to the application to the Family Court that was made by Carla's parents in this case), was that the surgical interventions that occurred — which were described as purely cosmetic in nature — were made by the parents and health care team without Court approval. This runs contrary to the principles in Marion's Case (Kelly and Smith 2017).

Kerridge, Lowe and Stewart state that:

the therapeutic/non-therapeutic distinction has completely broken down ... The distinction fails to tell us why some treatments need court approval and others do not... The better approach would be to jettison the distinction altogether and to work from an established list of treatments that require approval (Kerridge, Lowe, and Stewart 2013).

Aileen Kennedy (now a director of IHRA) describes the situation as one of 'complicity between the medical and the legal construction of variations of sex development as pathological disorders in urgent need of correction' where a 'tension between the medical and judicial responses to variations of sex development has disappeared' (Kennedy 2016).

9.2 Exemptions in legislation prohibiting female genital mutilation

Female Genital Mutilation (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.

Australia, in common with many other countries, maintains a legal prohibition on Female Genital Mutilation (FGM). Implementations of this prohibition facilitate unnecessary medical interventions on girls with atypical sex characteristics.

9.3 Australian Capital Territory

In 1997, the Crimes (Amendment) Act (No. 3) amended the Crimes Act 1900 to prohibit female genital mutilation, with no exemptions in relation to 'cultural, religious or other social custom' but an exemption for 'sexual reassignment procedures' meaning 'a surgical procedure performed by a medical practitioner to give a female person, or a person whose sex is ambivalent, the genital appearance of a person of the opposite sex or of a particular

sex (whether male or female)' (Australian Capital Territory 2018). This facilitates surgical interventions on girls with intersex traits that are prohibited on other girls.

9.4 New South Wales

In 1995, the Crimes Act 1900 was amended by the Crimes (Female Genital Mutilation) Amendment Act 1994. The provisions contain an exemption for medical procedures including 'sexual reassignment' constructed narrowly to mean surgeries to alter genital appearance 'to the appearance (as nearly as practicable) of the opposite sex to the sex of the person' (New South Wales 1994).

9.5 Northern Territory

In 1995, the Criminal Code Amendment Act (No. 2) amended the Criminal Code to prohibit female genital mutilation, with no exemptions in relation to 'cultural, religious or other social custom' but an exemption for 'gender reassignment' procedures meaning 'surgical procedure[s] to give a female, or a person whose sex is ambivalent, the genital appearance of a particular sex (whether male or female)' (Northern Territory 1983). This constructs an exemption permitting harmful practices on children with intersex variations.

Information available to us suggests that children in Northern Territory may be referred to Melbourne, Victoria, for surgery.

9.6 Queensland

In 2000, the Criminal Law Amendment Act prohibited female genital mutilation, with the exception of 'sexual reassignment' procedures defined as 'surgical procedure[s] to give a person the genital appearance of a particular sex, whether male or female' (Queensland 2019), constructing an exemption permitting harmful medical practices on children with intersex variations.

In 2008, the Health Legislation (Restriction on Use of Cosmetic Surgery for Children and Another Measure) Amendment Act prohibited some cosmetic interventions on children, but not procedures on the genitalia of infants and children with intersex variations.

As we identify earlier in this submission, feminising surgeries including procedures that 'enhanced the appearance of [a preschool child's] female genitalia' appear routine in Queensland, despite earlier assurances that irreversible procedures no longer occur (Department of Communities 2012; Carpenter 2018a; Adikari et al. 2019).

9.7 South Australia

In 1995, the Statutes Amendment (Female Genital Mutilation and Child Protection) Act prohibited female genital mutilation; it contains a narrow exemption for 'sexual reassignment procedures' including surgical procedures 'to give a female, or a person whose sex is ambivalent, genital characteristics, or ostensible genital characteristics, of a male', and an exemption for 'therapeutic' purposes 'directed at curing or alleviating a physiological disability or physical abnormality'.

In February 2022 the Minister for Health and Wellbeing wrote to Morgan Carpenter indicating support for current medical practices (Wade 2022).

9.8 Tasmania

In 1999, the Criminal Code Act 1924 is amended by commencement of the Criminal Code Amendment Act 1995, prohibiting female genital mutilation that prohibit procedures for cultural, religious or social customs, but that exempt 'sexual reassignment procedures' including 'a surgical procedure to give a female, or a person whose sex is ambivalent, the genital appearance of a particular sex' (Tasmania 2017).

In a letter to Morgan Carpenter dated 1 December 2021, the Minister for Health stated: 'I am advised that no surgeries to modify the sex characteristics of children are performed in Tasmania' (Rockliff 2021).

The president of the Australian Medical Association in Tasmania referred in the same year to surgeries on boys with atypical sex characteristics being necessary to ensure 'appropriate' urination (i.e. urination standing up) (McLennan 2021). Information available to us suggests that Tasmania exports a proportion of children to Melbourne for surgery.

9.9 Victoria

In 1996, the Crimes (Female Genital Mutilation) Act prohibited female genital mutilation with an exemption for 'sexual reassignment' procedures performed by medical practitioners. This appears to provide an exemption in relation to early surgical interventions on children with intersex variations.

In 2008, the Assisted Reproductive Technologies Act prohibited sex selection including reference to 'the purpose of a purpose of producing or attempted to produce a child of a particular sex', which an uninformed reader might take to mean a reference to include intersex people. However, the provisions exempt procedures that 'avoid the risk of transmission of a genetic abnormality or a genetic disease', and this provides a framework for the elimination of embryos with intersex variations.

Evidence available to us shows that so-called "corrective surgeries" persist in Victoria, and a key proponent of such practices has received one of Australia's highest awards for his services to paediatric surgery.

In 2021, IHRA and Equality Australia were contracted by the Victorian government to provide advice in relation to the drafting of legislation to protect the human rights of people with innate variations of sex characteristics in medical settings. No action has yet been confirmed.

9.10 Western Australia

The Gender Reassignment Act 2000 defines 'gender characteristics' and 'reassignment procedures' in relation to children (as well as adults) as follows:

gender characteristics means the physical characteristics by virtue of which a person is identified as male or female;

reassignment procedure means a medical or surgical procedure (or a combination of such procedures) to alter the genitals and other gender characteristics of a person, identified by a birth certificate as male or female, so that the person will be identified as a person of the opposite sex and includes, in relation to a child, any such procedure

(or combination of procedures) to correct or eliminate ambiguities in the child's gender characteristics; (Western Australia 2000)

Section 22 of the Criminal Code Amendment Act 2004 introduced a criminal prohibition of female genital mutilation, and explicitly excluded 'a reassignment procedure within the meaning of the Gender Reassignment Act 2000' from the scope of the prohibition (Western Australia 2004). These provisions are notable for facilitating surgical interventions on children where their sex characteristics ('gender characteristics') differ from gender stereotypes and other normative ideas for female or male bodies.

In a letter in May 2019 to our executive director Morgan Carpenter from Roger Cook MLA, in his capacity as Deputy Premier and Minister for Health, the Minister stated that:

Children with variations of sex development are offered individualised medical management and care in the public system at Perth Children's Hospital (PCH), including surgical care if required, as children with any other complex medical condition or variance would. [...]

Surgery may be indicated for children with variations of sex development for different medical reasons, ranging from reconstructive surgery for variances in development of genitalia, to surgery to minimise high cancer risk in the gonads. (Cook 2019)

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

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