



Submission to the Australian Human Rights Commission:

Protecting and promoting the human rights of people born with variations in sex characteristics in the context of medical interventions

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Thorne Harbour Health

Thorne Harbour Health is one of Australia's largest health and social service providers for the lesbian, gay, bisexual, trans and gender diverse, intersex, and other sex, sexuality and gender diverse (LGBTI+), and people living with HIV (PLHIV) communities. Its services include general practice, health promotion, counselling, housing support, family violence, and alcohol and other drug rehabilitation and harm reduction programs. Thorne Harbour Health primarily serves the populations of Victoria and South Australia, but also leads national projects. In partnership with other organisations, Thorne Harbour Health works to support all members of LGBTI+ and PLHIV communities, and is committed to improving the health and wellbeing of all LGBTI+ people and PLHIV.

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1. Introduction

Thorne Harbour Health welcomes the opportunity to present this submission to the Australian Human Rights Commission (AHRC) on the human rights of people born with variations in sex characteristics in the context of medical interventions. Thorne Harbour Health trusts that this submission will help inform the AHRC in its review of the current status of the enjoyment of human rights by people born with variations in sex characteristics in Australia.

This submission will focus on medically unnecessary interventions that alter, or are intended to alter, the sex characteristics of non-consenting individuals, as well as on reform strategies to facilitate substantive equality for intersex people. Parts of this submission build upon and are a modified version of a section of Thorne Harbour Health's May 2018 submission to the National Children's Commissioner on LGBTI Children's Rights.

Medically unnecessary interventions performed on non-consenting individuals born with variations in sex characteristics are an urgent and pressing human rights issue. Interventions that are not medically necessary are being performed on minors who lack the capacity to express a view about, or provide informed consent for, such interventions.

Medical narratives pathologise naturally-occurring sex variations as 'disorders of sex development' to be treated through procedures that arbitrarily assign a gender at birth, based on a socially constructed gender binary, for the purpose of 'normalising' or 'fixing' intersex bodies.

Many medical interventions on intersex people have no therapeutic benefit, and are often performed on non-consenting minors throughout infancy, childhood or adolescence. These interventions can lead to a number of further interventions throughout one's lifetime to maintain their assigned gender; it often begins in infancy and childhood with multiple genital 'normalising' surgeries or forced sterilisation, and is maintained with ongoing hormonal interventions.

This submission will detail why standards of care for intersex people are needed and the form they should take, support calls for the establishment of a special decision-making and review tribunal to ensure the standards of care are adhered to, and argue that once the standards of care are developed, that legislation should immediately be enacted to prohibit medical interventions that alter, or are intended to alter, the sex characteristics of non-consenting individuals.

2. Summary of recommendations

1. In reference to intersex people, 'people born with variations in sex characteristics' should be used instead of 'disorders of sex development'.
2. Australian medical bodies should adopt positions opposing medically unnecessary interventions that alter, or are intended to alter, the sex characteristics of non-consenting individuals.
3. Develop standards of care for intersex people that are consistent with international human rights law.
4. Involve human rights experts, child advocates, medical ethicists, child psychologists, medical doctors, and people with lived experience of intersex variations in the development of the standards of care for intersex people.
5. Incorporate a definition of 'medically necessary' interventions in the standards of care for intersex people, and establish medical necessity as the test for determining, at the level of clinical, tribunal or court decision-making, whether a particular intervention for a particular intersex variation at a particular time is permissible in the absence of an individual's own informed consent.
6. Require that in all decision-making there is consideration given to the lifelong health issues and the need for further interventions that arise as a consequence of the proposed interventions being performed.
7. Immediately following the development of standards of care for intersex people, enact legislation to establish a special decision-making and review tribunal to ensure the standards of care are adhered to.
8. Immediately following the development of standards of care for intersex people, enact legislation to prohibit medically unnecessary interventions that alter, or are intended to alter, the sex characteristics of non-consenting individuals.
9. Fund intersex organisations to advocate on behalf of intersex people, and to provide peer-based education and support services to parents of intersex children and medical professionals.
10. Fund the training of all health professionals that work with intersex people on the health needs and human rights of intersex people.
11. Fund independent and affirmative peer-based support groups that are inclusive and open to all individuals with intersex variations.

3. Terminology

3.1. What intersex is

'Intersex' is a term used to refer to people born with variations in sex characteristics, and is the preferred term used by advocates and intersex people. Intersex Human Rights Australia (IHRA, formerly OII), a leading intersex advocacy organisation, has provided the following definition of intersex:

Intersex is a term that relates to a range of congenital physical traits or variations that lie between ideals of male and female... it is a spectrum or umbrella term, rather than a single category.¹

In other words, intersex people have physical sex characteristics that do not fit typical notions of male or female bodies.² There are dozens of different intersex traits, and while some are apparent before or shortly after birth, others do not become apparent until puberty or adulthood. Estimates of intersex people vary, but it is likely they comprise 1-2% of the population.³

3.1.1. Sex characteristics

The *Yogyakarta Principles plus 10* defines 'sex characteristics' as "each person's physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones and secondary physical features emerging from puberty."⁴ The United Nations Office of the High Commissioner of for Human Rights has also used the term 'sex characteristics' to define intersex variations as a concept, describing intersex people as being "born with physical or biological sex characteristics (such asexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit the typical definitions for male or female bodies."⁵

3.2. What intersex is not

Intersex is about biology, not gender identity or sexual orientation. Simply put, sex is biological sex characteristics, gender is how one self-identifies, and sexual orientation relates to whom one is attracted. Intersex is not a third sex; it is a range of different variations of sex characteristics.

¹ Intersex Human Rights Australia. (2014). Making your service intersex friendly. p.2 <<https://ihra.org.au/wp-content/uploads/key/OII-Australia-Inclusive-Service.pdf>> (last accessed 05/10/18).

² Free & Equal. United Nations for LGBT Equality. Fact sheet: Intersex. <https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf> (last accessed 21/05/18).

³ Blackless, M., Charuvastra, C., Derryck, A. et al. (2000). How sexually dimorphic are we? Review and synthesis. *American Journal of Human Biology*, 12(2):151-166.

⁴ Yogyakarta Principles plus 10, preamble, p.6. <https://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf> (last accessed 03/10/18).

⁵ Office of the High Commissioner for Human Rights, African Commission on Human and Peoples' Rights, Council of Europe, Office of the Commissioner for Human Rights, Inter-American Commission on Human Rights, Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Special Rapporteur on violence against women, its causes and consequences, and Special Representative of the UN Secretary-General on Violence against Children. 2016. 'Intersex Awareness Day – Wednesday 26 October. End Violence and Harmful Medical Practices on Intersex Children and Adults, UN and Regional Experts Urge'. Office of the High Commissioner for Human Rights. <<https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&La>> (last accessed 03/10/18).

Being intersex is not the same as being transgender. Transgender people identify with genders that do not match the gender assigned to them at birth; although some intersex people are transgender, many are not, and in the cases intersex people seek gender affirmation, it is often not that they are transgender so much as it is they are reversing earlier inappropriate medical interventions. Like non-intersex people, intersex people have different sexual orientations and gender identities.

3.2.1. Disorders of sex development

Some in the medical profession now refer to people born with variations in sex characteristics as having ‘disorders of sex development’, a term that was introduced in a 2006 “Consensus statement on management of intersex disorders.”⁶ To call something a disorder is to assume it is not as it *should* be, but why *should* a human body be any particular way? As long as an individual is healthy, and their body is able to carry out the functions necessary for them to continue living, how can one fairly describe that person’s body as being disordered? Structural differences are not disorders. A more appropriate conceptualisation of a physical ‘disorder’ is dysfunction resulting in bodily harm.

Recommendation 1

In reference to intersex people, ‘people born with variations in sex characteristics’ should be used instead of ‘disorders of sex development’.

4. Physical & psychological harms

Surgical interventions on intersex people pose various physical and psychological harms, such as narrowing of the vagina (vaginal stenosis), scarring, sterility if the ovaries or testes are removed, and reduced sexual pleasure.⁷ Some intersex people report negative feelings associated with having undergone such interventions, and dissatisfaction with their overall genital appearance.⁸ A concerning proportion of female-assigned and surgically feminised children later reassign as male.⁹ Hormone interventions can have negative effects on fertility, metabolism, or the psychological wellbeing of intersex people.¹⁰

5. Human rights breaches

When performed without an individual’s own informed consent, or without an individual expressing a view in favour of and subsequently obtaining tribunal or court approval for,

⁶ Hughes, I.A., Houk, C., Ahmed, S.F., Lee, P.A. and LWPES/ESPE Consensus Group. (2006). Consensus statement on management of intersex disorders. *Archives of Disease in Childhood*, 91(7): 554–63.

⁷ Community Affairs References Committee. (2013). Involuntary or coerced sterilisation of intersex people in Australia. Paras 3.55-3.78; Creighton, S.M. (2004). Long-term outcome of feminization surgery: the London experience. *British Journal of Urology International*, 93(3):44-46.

⁸ Creighton, S.M. (2004). (n.7)

⁹ Reiner, W.G. and Gearhart, J.P. (2004). Discordant sexual identity in some genetic males with cloacal exstrophy assigned to female sex at birth. *New England Journal of Medicine*, 350:333-41.

¹⁰ Hewitt, J. and Zacharin, M. (2015). Hormone replacement in disorders of sex development: current thinking. *Best Practice & Research Clinical Endocrinology & Metabolism*, 29(3), 437-447.

medically unnecessary interventions that alter, or are intended to alter, sex characteristics, such interventions violate several human rights, including the right to security of person, the right to freedom from all forms of violence, the right to the highest attainable standard of health and the right to freedom from torture or ill treatment.¹¹

These practices clearly cannot be in the best interests of intersex children,¹² as they represent violence against intersex children: they breach the right not to be subject to torture or other cruel, inhuman or degrading treatment or punishment,¹³ and they represent physical abuse that can result in psychological trauma.¹⁴

The *Yogyakarta Principles* are a significant supplement to international human rights law, aiming to provide a consistent understanding of human rights norms as they relate to sexual orientation, gender identity, and intersex status. The *Yogyakarta Principles Plus 10*, introduced in 2017, address issues specific to those born with variations in sex characteristics, affirming the right to bodily and mental integrity as part of the highest attainable standard of health. They appeal for the prohibition of “invasive or irreversible medical procedures that modify sex characteristics without... free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person.”¹⁵

6. Consent & ethical concerns

Intersex children are subject to medically unnecessary procedures when they are too young to understand, consent to, or protest against them. Surgical interventions most often occur during childhood, and hormonal interventions, which we have heard can be initiated on infants only a few months old,¹⁶ may be lifelong. Importantly, despite medical interventions almost always being medically unnecessary, the consent of the intersex child is, to our knowledge, almost never obtained. Instead, consent is obtained from parents or guardians, or via the Family Court. An additional concern is the considerable pressure that parents or guardians may feel in consenting to proposed medical interventions.¹⁷

Even when intersex children are old enough to have some form of understanding and to protest, as long as there is parental consent, the child undergoes medically unnecessary interventions against their views. This clearly does not give regard to the views of the child.¹⁸ It also represents a double standard that breaches the right to non-discrimination.¹⁹ Parents do not have a right to consent to similar medically unnecessary alterations of sex characteristics for non-intersex girls, which are criminalised in every state and territory as

¹¹ Meddings, J.I. and Wisdom, T.L.C. (2017). Genital autonomy. Rationalist Society of Australia.

<https://www.academia.edu/32477639/RSA_White_Paper_Genital_Autonomy> (last accessed 05/10/18).

¹² Convention on the Rights of the Child, Article 3.

¹³ Ibid. Article 37(a).

¹⁴ Ibid. Articles 19 and 39.

¹⁵ Yogyakarta Principles Plus 10. (2017). The Yogyakarta Principles Plus 10: Additional Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics, to Complement the Yogyakarta Principles. p.10.

<<http://www.yogyakartaprinciples.org/principles-en/vp10/>> (last accessed 05/10/18).

¹⁶ Personal communication, Tony Briffa, Co-Executive Director Intersex Human Rights Australia (22/09/18).

¹⁷ Community Affairs References Committee. (2013). (n.7). paras 1.52, 2.31 and 3.83.

¹⁸ Convention on the Rights of the Child. Article 12.

¹⁹ Ibid. Article 2.

female genital mutilation.²⁰ In the absence of medical necessity, then, parents should likewise be unable to consent to such procedures for intersex children.

In *Marion's Case*, the High Court of Australia clarified which types of medical procedures fall outside the scope of parental responsibility and therefore require court authorisation:

sterilisation requires invasive, irreversible and major surgery. But so do, for example, an appendectomy and some cosmetic surgery, both of which, in our opinion, come within the ordinary scope of a parent to consent to. However, other factors exist which have the combined effect of marking out the decision to authorise sterilisation as a special case. Court authorisation is required, first, because of the significant risk of making the wrong -----decision, either as to a child's present or future capacity to consent or about what are the best interests of a child who cannot consent, and secondly, because the consequences of a wrong decision are particularly grave.²¹

The requirement of court oversight acts as a 'procedural safeguard' for children's rights, particularly their rights to personal inviolability and bodily integrity.²² *Marion's Case* provided the foundation for the Family Court of Australia's 'special medical procedures' case law, in which the Family Court determines on a case-by-case basis if proposed medical procedures require court approval. Such cases have established that 'special medical procedures' are not limited to sterilisation procedures for minors with intellectual disabilities, and can include procedures that do not have a sterilising effect.²³

Significantly, in *Marion's Case* the High Court referred to views expressed in the Family Court decision of *In Re Jane* (1988) 94 FLR 1, in which Nicholson CJ noted:

[t]he consequences of a finding that the court's consent is unnecessary are far reaching both for parents and for children. For example, such a principle might be used to justify parental consent to the surgical removal of a girl's clitoris for religious or quasi cultural reasons, or the sterilisation of a perfectly healthy girl for misguided, albeit sincere, reasons. Other possibilities might include parental consent to the donation of healthy organs such as a kidney from one sibling to another.²⁴

Nicholson CJ's view should be applied to clitoral surgeries on girls with intersex variations where performed for psychosocial reasons and without medical necessity. Moreover, all medically unnecessary modifications of children's sex characteristics arguably fulfil the test from *Marion's Case* for psychosocial reasons, and therefore all such procedures should require the approval of a special tribunal or the Family Court.

Parents and guardians should not be able to consent to medically unnecessary modifications of children's sex characteristics. Children are not the property of their parents; they are individual bearers of rights, and they enjoy these rights independently of their parents.²⁵ If an individual is too young to provide informed consent to a medically unnecessary procedure, then by virtue of that procedure being medically unnecessary it is deferrable, and ought to be

²⁰ *Crimes Act 1958* (Vic) s 32; *Criminal Code Act 1924* (Tas) s178A; *Crimes Act 1900* (NSW) s 45; *Crimes Act 1900* (ACT) s74; *Criminal Law Consolidation Act 1935* (SA) s 33A; *Criminal Code Act 1899* (Qld) s 323A; *Criminal Code Act 1983* (NT) Schedule 1 cl 186B; *Criminal Code* (WA) s 306

²¹ *Secretary of the Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218, 250 (Mason CJ, Dawson, Toohey, and Gaudron JJ).

²² *Ibid.*

²³ *In the Marriage of GWW and CMW* (1997) 21 Fam LR 612.

²⁴ *In Re Jane* (1988) 12 Fam LR 662, 685 (Nicholson CJ).

²⁵ Swatek-Evenstein, M. (2013). Limits of enlightenment and the law – on the legality of ritual male circumcision in Europe today. *Utrecht Journal of International and European Law*, 29(77):42-50.

deferred until the individual concerned is old enough provide informed consent as a Gillick competent minor, or to express a view in favour of such interventions and obtain tribunal or court approval for them.²⁶ Such an approach affords greater respect for, and protection of, the fundamental rights of the child.

7. International developments

In 2015, Malta became the first country to enshrine the right to “bodily integrity and physical autonomy” into law and ban non-consensual, medically unnecessary modifications of children’s sex characteristics.²⁷ Malta’s legislation states that it is “unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent.”²⁸

Chile briefly followed Malta in protecting intersex children from unnecessary medical interventions. In December 2015, the Chilean Ministry of Health issued ‘Circular No. 8’, a non-binding regulatory suspension of ‘normalising’ surgeries, instructing that they be deferred until the child could provide free, prior and informed consent. However, these guidelines were overturned in August 2016 with ‘Circular No. 7’, permitting surgical interventions to be performed where ‘a clearly defined sex’ can be determined in the intersex variation, and providing clinical guidance for specific variations. The guidelines consider the possibility of deferring surgery until the child manifests a gender identity, and obtaining the opinion of multidisciplinary teams in decisions related to sex assignment surgeries.

In 1999, the Colombian Constitutional Court was the first to give judicial consideration to human rights protections for intersex people. Although medical interventions are not prohibited, a series of judicial decisions guide current practice.²⁹ The Court has expressly affirmed the right of the child to bodily autonomy and to developing a gender identity, holding that the sex of a child should not be altered without informed consent. The Court has also held that the child’s autonomy increases with age, restricting parental consent for medical interventions to children under the age of five. However, this decision was made with respect to a child who was eight years old at the time; intersex activists have expressed concern that the court’s decision will expedite medical procedures for intersex children at the point of birth.³⁰

In Germany, two cases of legal action against harmful and non-consensual medical intervention awarded compensation for damages caused by surgical and hormonal treatment. The second of these cases returned a successful verdict of institutional liability in December 2015, due to a failure to properly advise the individual about their intersex variation.

A bill is currently before the California state legislature that condemns medically unnecessary procedures on children with variations in sex characteristics, “recognizes that intersex children should be free to choose whether to undergo life-altering surgeries that irreversibly—and sometimes irreparably—cause harm”, and calls upon the “health

²⁶ *Gillick v West Norfolk and Wisbech AHA*. (1986) AC 112 ((HL)).

²⁷ *Gender Identity, Gender Expression and Sex Characteristics Act* (Malta) s3(d) <<https://rm.coe.int/168045b1e6>> (last accessed 18/12/17).

²⁸ *Ibid.* s15(1).

²⁹ Sentencia T-477/95.

³⁰ Holmes, Morgan (2006). Deciding fate or protecting a developing autonomy? Intersex children and the Colombian Constitutional Court. *Transgender Rights*. Minneapolis, Minnesota: University of Minnesota Press. pp. 32–50.

professions to foster the well-being of children born with variations of sex characteristics, and the adults they will become, through the enactment of policies and procedures that ensure individualized, multidisciplinary care that respects the rights of the patient to participate in decisions, defers medical or surgical intervention, as warranted, until the child is able to participate in decision making, and provides support to promote patient and family well-being.”³¹

8. Significant reports

8.1. International

In 2015, following the enactment of the Maltese legislation, the Office of the High Commissioner for Human Rights (OHCHR) called for a ban on medically unnecessary procedures on intersex children. This was followed by twelve UN bodies, including the OHCHR, the United Nations Children’s Fund and the World Health Organization releasing a joint statement that condemned such medically unnecessary procedures on intersex children as “abuse in a medical setting.”³²

In 2016, the UN Special Rapporteur on Torture called upon states to repeal laws that allow “intrusive and irreversible treatments [including] genital normalising surgeries” on intersex people,³³ as such practices constitute torture and ill-treatment in a health-care setting.³⁴

In June 2017, three former U.S. Surgeon Generals released the following statement:

“When an individual is born with atypical genitalia that pose no physical risk, treatment should focus not on surgical intervention but on psychosocial and educational support for the family and child. Cosmetic genitoplasty should be deferred until children are old enough to voice their own view about whether to undergo the surgery.”³⁵

In October 2017, Physicians for Human Rights, a co-recipient of the Nobel Peace Prize, released a statement opposing medically unnecessary surgeries performed without an individual’s informed consent:

“Physicians for Human Rights (PHR) today called for an end to all medically unnecessary surgical procedures that seek to alter gonads, genitals, or internal sex organs of children born with atypical sex characteristics, until the child is old enough to participate meaningfully in decisions about their body and health...

Physicians for Human Rights is deeply alarmed by the fact that children born with atypical sexual characteristics – sometimes referred to as intersex children, or children with intersex variations – are often subjected to irreversible and medically

³¹ California Legislative Counsel. Resolution Chapter 225. Senate Concurrent Resolution No. 110—Relative to sex characteristics. Filed 11 September 2018.

<https://leginfo.ca.gov/faces/billTextClient.xhtml?bill_id=201720180SCR110> (last accessed 05/10/18).

³² Office of the High Commissioner for Human Rights, et al. (September 2015). *Ending Violence and Discrimination against Lesbian, Gay, Bisexual, Transgender and Intersex People*.

<http://www.ohchr.org/Documents/Issues/Discrimination/Joint_LGBTI_Statement_ENG.PDF> (last accessed 04/10/18).

³³ Méndez, J.E. (2016) Report of the special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, 31st sess, Agenda Item 3, UN Doc A/HRC/31/57, para 72(i).

³⁴ Ibid. para 48.

³⁵ Elders, M.J., Satcher, D. and Carmona, R. (2017). Re-thinking genital surgeries on intersex infants. Palm Center.

unnecessary surgeries that seek to alter their gonads, genitals, and/or internal sex organs before they are able to provide informed consent. These surgeries, which can result in sterilization and decreased sexual function, among other negative health outcomes, have been highlighted by United Nations human rights and health experts as counter to the absolute prohibition of cruel, inhuman, and degrading treatment, and as compromising the human rights to physical integrity and health. From a medical ethics perspective, carrying out an irreversible and medically unnecessary surgery before a child is old enough to consent violates internationally recognized informed consent requirements, and violates the obligation to do no harm.”³⁶

In February 2018, Dainius Pūras, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and Nils Melzer, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, wrote to the American Academy of Pediatrics³⁷ and American Medical Association,³⁸ urging both organisations to adopt a policy that respects the “fundamental human rights of intersex children and adults to health, to physical and mental integrity, [and] to live free from violence and harmful practices and to be free from torture and ill-treatment.”

8.2. Regional

In 2013, the Australian Parliament Senate Community Affairs References Committee (the Senate Committee) conducted an inquiry into the involuntary or coerced sterilisation of intersex people.³⁹ The Senate Committee made recommendations aimed at reducing non-consensual modifications of intersex people’s sex characteristics. It also recommended that all intersex medical procedures be managed by multidisciplinary teams within a human rights framework, and require authorisation by a civil and administrative tribunal or the Family Court. It has now been five years since the Committee made its recommendations, and to date, there has been no action taken to implement them.

In 2013, the Victorian Department of Health and Human Services published a document titled *Decision-making principles for the care of infants, children and adolescents with intersex conditions*.⁴⁰ This document highlighted medical management, human rights, ethical, and legal principles, as well as principles for supporting patients and parents, and detailed how these principles should be applied. Importantly, the decision-making principles stated that:

“All decisions about the healthcare of infants, children and adolescents with intersex conditions in Victoria should be made in the best interests of the patient, according to current best practice principles for supporting patients and parents, and in consideration of the medical management, human rights, ethical and legal decision-making principles...”

³⁶ Physicians for Human Rights. (20/10/17). Unnecessary surgery on intersex children must stop. <<https://phr.org/news/unnecessary-surgery-on-intersex-children-must-stop/>> (last accessed 05/10/18).

³⁷ Pūras, D. and Melzer, N. (01/02/18). Mandates of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. REFERENCE: OL OTH 5/2018. <<https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gld=23618>> (last accessed 05/10/18).

³⁸ Pūras, D. and Melzer, N. (01/02/18). Mandates of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. REFERENCE: OL OTH 4/2018. <<https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gld=23617>> (last accessed 05/10/18).

³⁹ Community Affairs References Committee. (2013). (n.7).

⁴⁰ Department of Health and Human Services. (2013). Decision-making principles for the care of infants, children and adolescents with intersex variations. Victorian Government. <<https://www2.health.vic.gov.au/about/publications/policiesandguidelines/Decisionmaking-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions>> (last accessed 05/10/18).

However, the decision-making principles only act as resource to guide decisions, and are not legally enforceable. Moreover, the medical management principles outlined do not refer to the need to adhere to a consent model in which an individual to be subject to medically unnecessary procedures first provides their own informed consent, or is at least able to express a view in favour of having them performed.

In 2017, intersex organisations in Australia and New Zealand released the Darlington Statement, which acknowledged the right of intersex people to bodily autonomy and called for the prohibition of all deferrable medical interventions on intersex infants and children.⁴¹ In 2018, intersex allies were invited to become signatories to the Darlington Statement, and the number of signatories continues to grow.⁴²

In September 2018, thirty LGBTI+ organisations and service providers endorsed an *LGBTI+ Priorities* document ahead of the Victorian state election, which among other things outlined support for intersex Victorians. Some of the actions called for included:

- the development of standards for the care of intersex children that prevent medically unnecessary interventions from occurring without the individual's own informed consent;
- the establishment of a specialist administrative tribunal that includes human rights experts, child advocates, medical ethicists, and people with lived experience of intersex variations that is responsible for approving interventions on intersex children and reviewing medical decisions to perform interventions without prior tribunal approval due to their being deemed too medically urgent to wait;
- adequately resourced access to peer-based education and support services; and
- the prohibition of non-consensual, medically unnecessary modifications of sex characteristics.⁴³

9. Rationales for interventions

Medical interventions on intersex children are currently performed based on gender stereotypes, social norms, or technical or financial rationales. None of these rationales are sufficient to warrant the medically unnecessary alteration of an individual's sex characteristics without their consent.

9.1. Historical context

The current approach to children born with sex characteristics that are not typically male or female is for parents to choose a sex based on the advice of doctors and for sex reassignment procedures to occur. This approach is largely based on the influence of John Money, a sexologist from Johns Hopkins University, who developed an 'optimal gender theory'. According to Money's theory, which emerged in the latter half of the 20th century, gender identity is not fixed and is considered to develop at around the age two. While a number of variables are said to contribute to the development of gender identity, of particular

⁴¹ Darlington Statement. (March 2017). Joint consensus statement from the intersex community retreat in Darlington, March 2017. <<https://ihra.org.au/wp-content/uploads/key/Darlington-Statement.pdf>> (last accessed 04/10/18).

⁴² The Darlington Statement <<https://darlington.org.au/signatories/>> (last accessed 04/10/18).

⁴³ Victorian Gay and Lesbian Rights Lobby. Rainbow Votes. <<http://vqlrl.org.au/rainbow-votes-2018/>> (last accessed 04/10/18).

significance is how children were “reared, as long as the rearing does not clash with visible anatomy.”⁴⁴ It has been suggested that Money’s theory promised a cure for intersex:

[t]he combination of relative gender fluidity and surgical innovation meant that intersex children could literally be reshaped into males and females.⁴⁵

Based on this theory, Money and his team constructed comprehensive treatment and management protocols that not only influenced medical literature, but governed medicalisation of intersex variations for decades and continue to linger in current practices.⁴⁶

9.2. Current practice

Intersex political advocacy, and academic and clinical criticism undermined Money’s treatment protocols, and to some extent shifted a rhetoric that carried significant clinical legitimacy. An international symposium was convened to revisit the existing protocol, which led to the development of the 2006 guidelines, also known as the ‘consensus statement’.⁴⁷ These guidelines set the benchmark for the medical treatment of intersex people, and continue to steer current practice today. Although the 2006 guidelines purport to improve the practices associated with Money’s theory, they continue to sanction ‘genital normalisation’ surgery in infants, based on vague and imprecise criteria.⁴⁸ A lack of uniform standards of care or treatment guidelines means that current practice is difficult to discern. It represents a major gap in the provision of equitable healthcare for intersex people.

In its 2013 Report, the Victorian Department of Health expressly endorsed the 2006 practice guidelines, and implicitly endorsed the continued practise of ‘genital normalising surgery’ in Australia. The Report also indicated that infants who receive an intersex variation diagnosis in Victoria are referred for assessment at either the Royal Children’s Hospital or the Monash Medical Centre:

“...in 2011, Victorian hospitals reported seeing approximately 40 new cases of infants with identified intersex conditions per year, and involvement in follow up and monitoring for 240 patients into childhood and adolescence.”⁴⁹

In 2016, an update to the 2006 ‘consensus statement’ acknowledged the scarcity of its evidence-base:

There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of [disorders of sex development] surgery. The levels of evidence of responses given by the experts are low... Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated [disorders of sex development] during childhood for the individual, the parents, society or the risk of stigmatization.⁵⁰

⁴⁴ Kennedy, A. (2016). Fixed at Birth: Medical and Legal Erasures of Intersex Variations. *University of New South Wales Law Journal*, 30; (2016) 39(2) *University of New South Wales Law Journal*, pp.813, 819.

⁴⁵ Ibid, p.819.

⁴⁶ Ibid, p.826.

⁴⁷ Hughes, I.A. et al. (2006). Consensus Statement on Management of Intersex Disorders. *Pediatrics*, 91:554.

⁴⁸ Kennedy, A. (2016). (n.44) pp. 813, 819.

⁴⁹ Department of Health and Human Services (2013). (n.40). p.1.

⁵⁰ Lee, Peter A., Anna Nordenström, Christopher P. Houk, S. Faisal Ahmed, Richard Auchus, Arlene Baratz, Katharine Baratz Dalke, et al. 2016. ‘Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care’. *Hormone Research in Paediatrics*, 85(3):158–180.

A range of often contradictory rationales are advanced in an array of different documents, pointing to the inconsistency of current clinical practice, and incoherent understandings of the specific needs of intersex people.

9.3. Social rationales

So-called ‘normalizing’ sex reassignment surgery is performed on young children so they conform to arbitrary social ‘norms’ that correspond to binary gender stereotypes, in order to alleviate the parental concern that their intersex children might in the future suffer psychological harm from bullying.⁵¹ Inflicting a present physical harm in anticipation of a possible future psychological harm is nonsensical. It appears this rationale shifts the focus away from what is best for the child to what is more comforting for their parents. Social, aesthetic and parental concerns are advanced as rationales for female genital mutilation,⁵² and the law does not accept these rationales as sufficient to justify the practice. Likewise, they should not be considered sufficient to justify interventions that alter, or are intended to alter, the sex characteristics of any non-consenting individual.

9.4. Technical rationales

Technical considerations associated with surgery, such as the relative ease of constructing a vagina compared with relative difficulty of constructing a phallus, shift the focus away from the what is best for the child to what is easiest for the surgeon. They also appeal to gender stereotypes, and the surgical convenience of altering the intersex variation to best ‘present’ that gender. Such surgical procedures prescribe gender without regard for the child’s future desires or gender identity, which cannot be predicted with any accuracy.

9.5. Financial rationales

Financial considerations should not inform whether or not children receive care that is in their best interests. Surgical intervention should not be cast as a complete ‘fix-all’ solution for complex psychosocial issues that may arise in the course of the child’s life. Individuals and their families must feel supported in their decisions, and not be pressured into pursuing one option due to real or perceived financial rationales.

9.6. Cancer risk

The point at which pre-emptive surgery to remove tissue that has the *potential* to become cancerous becomes advisable is an open question. Data on cancer risk in intersex people is very limited due to the already high rate of such pre-emptive surgeries making control groups difficult to establish. Many oncologists also advise a ‘wait-and-watch’ approach for the treatment of certain cancers *even once detected*, so the medical justification for pre-emptive surgical removal of tissue that merely has the potential to become cancerous in intersex children is at best unclear. Indeed, it appears that other rationales unrelated to physical health impact such decision-making.⁵³ Standards of care for intersex people must

⁵¹ Community Affairs References Committee. (2013). (n.7). paras 1.51-1.55, 3.128.

⁵² World Health Organization, Office of the High Commissioner for Human Rights, UNAIDS, UNDP, UNECA, UNESCO, UNFPA, UNHCR, and UNIFEM, eds. 2008. *Eliminating Female Genital Mutilation: An Interagency Statement*. Geneva: World Health Organization. <http://www.un.org/womenwatch/daw/csw/csw52/statements_missions/Interagency_Statement_on_Eliminating_FGM.pdf> (last accessed 03/10/18).

⁵³ Cools, M., Dessens, A., Drop, S., Hewitt, J. and Warne, G. (2013). ‘Answers to Questions on Notice (Received 27 Sep 2013)’. In Chapter 4: Intersex and Cancer. *Involuntary or Coerced Sterilisation of Intersex People in Australia*. Parliament of Australia.

address the risk threshold that needs exceeded for such pre-emptive procedures to be considered medically necessary. In the absence of data supporting that risk, such surgical interventions should be deferred. Ethically speaking, that a complication may later arise is not sufficient grounds for invasive and irreversible medical intervention, whether surgical or hormonal, in cases an individual's informed consent has not been obtained.

9.7. Permissible rationales

The only permissible rationale for an intervention that alters, or is intended to alter, the sex characteristics of a non-consenting individual should be that such an intervention is medically necessary; in the case of non-consenting minors, it is only medically necessary interventions that are in the best interests of the child.

The best interest principle is enshrined in the Convention on the Rights of the Child. The principle of the best interests of the child is codified in the *Family Law Act 1975* (Cth), and this best interests test is often deployed as a 'paramount consideration' in Family Law matters. While in principle, the best interests principle has virtuous overtones, in practice, judicial considerations tend to obfuscate the "true situation" in a manner that appeals to the parent's own interests, by weighing them against the child's.⁵⁴

One solution that would better protect the best interests of the child, as opposed to the interests of their parents, would be for the *Family Law Act 1975* (Cth) to be amended to include a provision that expressly allows the court to consider human rights as an additional consideration in the determination of best interests pursuant to section 60CC of the Act. Another solution would be to bring the best interests test of the Act in line with the *Yogyakarta Principles plus 10*, namely Principle 32:

- D) Bearing in mind the child's right to life, non-discrimination, the best interests of the child, and respect for the child's views, ensure that children are fully consulted and informed regarding any modifications to their sex characteristics necessary to avoid or remedy proven, serious physical harm, and ensure that any such modifications are consented to by the child concerned in a manner consistent with the child's evolving capacity;
- E) Ensure that the concept of the best interest of the child is not manipulated to justify practices that conflict with the child's right to bodily integrity.⁵⁵

In the absence of medical necessity, such interventions must be deferred until a minor can express a clear view for such interventions to occur and obtain tribunal or court approval, or until they are able to provide informed consent as a Gillick competent minor.

The right of parents to make medical decisions on behalf of their children, *when they have to*, is not in question. However, no parent should have the right to permanently alter their child's sex characteristics, through the amputation and surgical manipulation of tissue, or administration of hormones, or however else, when doing so is medically unnecessary. Furthermore, even in cases where medical interventions are necessary, and parental consent is required, the right of parents to make medical decisions on behalf of their children is still limited by the parental responsibility to do what is in the best interests of the child. Parents must therefore be fully informed of the risks and benefits of such procedures, and it is not clear to us, based on discussions with the intersex community, that this is occurring at

<http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index> (last accessed 05/10/18).

⁵⁴ Dickey, A. (2011) 'The Best Interests of the Child Doctrine: Truth, Ideology Or Mantra', *Australia Law Journal*, 85, 159.

⁵⁵ Yogyakarta Principles (2017). (n.15). p.10.

present. Moreover, it has previously been identified that parents and guardians may feel considerable pressure to make treatment decisions quickly based on medical advice.⁵⁶

10. Medical attitudes in Australia

10.1. Australian Paediatric Endocrine Group

In 2013, the Australian Paediatric Endocrine Group, in its submission to the Senate Inquiry Into the Involuntary or Coerced Sterilization of People with Disabilities in Australia, stated that:

“Indications for surgery in [disorders of sex development] involve... [the] 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...⁵⁷

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 rearing⁵⁸

There is limited evidence reporting long-term outcomes of early surgical management for reasons of appearance. The few outcome studies reported have conflicting results of good and poor outcomes (cosmetic, sexual, or psychological), with particular concern regarding sexual function and sensation.”⁵⁹

This statement conflates gender identity with biological sex, and admits there is little evidence supporting the cosmetic surgical management of children with variations in sex characteristics. This is an astonishing admission, given the procedures are frequently performed despite the lack of supporting medical evidence, and indeed despite evidence of the harms associated with such medically unnecessary surgical interventions.

10.2. Australian Medical Association

In 2014, the Australian Medical Association released a statement on sexual and reproductive health stating that, “Intersex... people should have equitable access to quality sexual and reproductive healthcare, and to health services that are inclusive, free of discrimination and stigma, and responsive to their individual healthcare needs.”⁶⁰ ‘Gender affirmation surgery’ was viewed as a medical procedure rather than a cosmetic procedure, that was necessary and beneficial for intersex people who sought such intervention. The statement continued,

⁵⁶ Community Affairs References Committee. (2013). (n.7). paras 1.52, 2.31 and 3.83.

⁵⁷ Australasian Paediatric Endocrine Group. (27/06/13). Submission of the Australasian Paediatric Endocrine Group to the Senate Inquiry into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development. Submission 88, p.3.

⁵⁸ Ibid, p.4.

⁵⁹ Ibid, p.4.

⁶⁰ Australian Medical Association. (2014). Position statement: sexual and reproductive health. p.5.

<https://ama.com.au/sites/default/files/documents/position_statement_on_sexual_and_reproductive_health_2014_0.pdf> (last accessed 05/10/18).

however, to assert that ‘normalising cosmetic genital surgery’ on intersex infants “should be avoided until a child can fully participate in decision making.”⁶¹

10.3. Royal Australasian College of Physicians

In 2015, the Royal Australasian College of Physicians issued a position statement that described the right to bodily integrity as the position of third parties, and which endorsed psychosocial rationales for decision-making for interventions on individuals with intersex variations:

“International human rights institutions state that medical interventions for cosmetic or psychosocial reasons should not take place until the person concerned can provide free and fully informed consent. This includes surgical and hormonal interventions, and respect for the right of persons with intersex variations not to undergo sex assignment treatment. The Organisation Intersex International Australia has also advocated on these issues.

Individuals with intersex variations require subspecialist care by expert multidisciplinary management teams, with careful consideration of the issues that can be raised in these conditions, including minimising physical and psychosocial risk, preserving potential for fertility, preserving or promoting capacity to have satisfying sexual relations, and leaving options open for the future.”⁶²

Recommendation 2

Australian medical bodies should adopt positions opposing medically unnecessary interventions that alter, or are intended to alter, the sex characteristics of non-consenting individuals.

11. Administrative & legislative reform

11.1. Standards of care

Nationally consistent standards of care for intersex people should be developed. These standards of care must be consistent with international human rights law, and should be developed by human rights experts, child advocates, medical ethicists, child psychologists, medical doctors, and people with lived experience of intersex variations. This process should be facilitated by the Department of Health, not by hospitals or peak medical bodies. The standards of care must incorporate a definition of ‘medically necessary’ interventions, which should be the test for whether particular interventions for particular intersex variations at particular times are permissible. The standards of care must also require that in all decision-making there is consideration given to future interventions that will be, or are likely to be, required as a result of the proposed interventions being performed. To ensure the standards

⁶¹ Ibid, p.12.

⁶² Royal Australasian College of Physicians. (2015). Sexual and reproductive health care for young people: position statement. pp.28-29. <<https://www.racp.edu.au/docs/default-source/advocacy-library/pa-ps-sexual-and-reproductive-health-care-for-young-people.pdf>> (last accessed 05/10/18).

of care are adhered to, legislation should be enacted that establishes a special decision-making and review tribunal, and prohibits medically unnecessary interventions that alter, or are intended to alter, the sex characteristics of non-consenting individuals.

11.1.1 Need to incorporate medical necessity

In addition to embedding the consideration of human rights, key to the success of the standards of care in preventing medically unnecessary interventions from being performed on non-consenting individuals, will be that they incorporate a definition of ‘medically necessary’ interventions, and for ‘medical necessity’ to be the test for determining whether a particular intervention for a particular intersex variation at a particular time is permissible.

11.1.2. Need to consider future interventions

As the AHRC noted in its consultation paper for this inquiry, “Interventions are... not necessarily single, discrete events and may require ongoing management and further interventions in the future.”⁶³ For example, in a study of 44 adolescent girls born with intersex variations that had multiple feminising surgeries during childhood, almost all required further surgery to facilitate menstrual flow, vaginal intercourse, or both.⁶⁴ For this reason, the standards of care will also need to require that in all decision-making there is consideration given to the lifelong health issues and future interventions that will be, or are likely to be, required as a result of proposed interventions being performed.

Recommendation 3

Develop standards of care for intersex people that are consistent with international human rights law.

Recommendation 4

Involve human rights experts, child advocates, medical ethicists, child psychologists, medical doctors, and people with lived experience of intersex variations in the development of the standards of care for intersex people.

Recommendation 5

Incorporate a definition ‘medically necessary’ interventions in the standards of care for intersex people, and establish medical necessity as the test for determining, at the level of clinical, tribunal or court decision-making, whether a particular intervention for a particular intersex variation at a particular time is permissible in the absence of an individual’s own informed consent.

Recommendation 6

Require that in all decision-making there is consideration given to the lifelong health issues and the need for further interventions that arise as a consequence of the proposed interventions being performed.

⁶³ Australian Human Rights Commission. (July 2018). Protecting the human rights of people born with variations in sex characteristics in the context of medical interventions. Consultation paper. para 89, p.18. <https://www.humanrights.gov.au/sites/default/files/AHRC_Consultation%20paper_2018_2.pdf> (last accessed 02/10/18).

⁶⁴ Creighton, S.M., Minto, C.L. and Steele, S.J. (2001). Objective cosmetic and anatomical outcomes at adolescence of feminising surgery for ambiguous genitalia done in childhood. *Lancet*, 358:124-5.

11.1.3 Special decision-making and review tribunal

Once the standards of care are developed, legislation should immediately be enacted to establish a special decision-making and review tribunal to ensure the standards are adhered to. The special tribunal should comprise human rights experts, child advocates, medical ethicists, child psychologists, medical doctors, and people with lived experience of intersex variations. The special tribunal would approve medical interventions in line with the standards of care, and any relevant legislation, and review medical decisions to undertake such interventions made without prior tribunal approval, due to their being deemed too medically urgent to wait. Determinations or declarations made by the special tribunal could be appealed to a court.

Recommendation 7

Immediately following the development of standards of care for intersex people, enact legislation to establish a special decision-making and review tribunal to ensure the standards of care are adhered to.

11.2. Medical necessity

The definition of ‘medically necessary’ interventions could be defined within the standards of care, but ideally would be enshrined in legislation that establishes a special decision-making and review tribunal and prohibits medically unnecessary interventions that alter, or are intended to alter, the sex characteristics of non-consenting individuals.

11.2.1. Therapeutic v. non-therapeutic

Case law provides us with a distinction between ‘therapeutic’ and ‘non-therapeutic’ medical treatment, as defined according to Brennan J’s dissenting judgment in *Marion’s Case*:

It is necessary to define what is meant by therapeutic medical treatment. 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.⁶⁵

It also provides us with legal factors which determine the therapeutic nature of medical treatment:

Proportionality and purpose are the legal factors which determine the therapeutic nature of medical treatment. Proportionality is determined as a question of medical

⁶⁵ *Marion’s Case* (1992) 175 CLR 218, 269 (Brennan J). Although Brennan J dissented in *Marion’s Case*, his Honour’s views concerning the distinction between therapeutic and non-therapeutic procedures was not in dissent. See: *Re Kelvin* (2017) 351 ALR 329, 349 at 132 (Thackray, Strickland, and Murphy JJ).

fact. Purpose is ascertained by reference to all the circumstances but especially to the physical or mental condition which the treatment is appropriate to affect.⁶⁶

11.2.2. Therapeutic v. medically necessary

In the context of interventions that alter, or are intended to alter, sex characteristics, there is a need to further distinguish between interventions that are ‘therapeutic’ and interventions that are ‘medically necessary’. An intervention being merely therapeutic is too low a bar to set for permitting an unnecessary and deferrable intervention on a non-consenting individual, particularly when that intervention results in irreversible changes to their bodily sex characteristics, is inherently harmful, or the benefits of the intervention do not outweigh the intrinsic harms and associated risks.

Section 34A (1)(a) of the *Crimes Act 1958* (Vic) provides an exception to the offence of female genital mutilation, when a surgical operation is “necessary for the health of the person on whom it is performed and which is performed by a medical practitioner”, and section 34A (2)(a) states that “For the purposes of subsection (1)(a), in determining whether an operation is necessary for the health of a person, the only matters to be taken into account are those relevant to the medical welfare or the relief of physical symptoms of the person.” Such a definition of medical necessity is not sufficient to protect intersex children from medically unnecessary interventions. Unlike female genital mutilation, which is roundly condemned by Australia’s peak medical bodies, many doctors consider people with intersex variations to have a ‘disorder of sex development’ in need of correction, and Australia’s peak medical bodies have at best failed to take a strong stance against non-consensual, medically unnecessary ‘normalising’ interventions that alter sex characteristics, and at worst tacitly supported the sex reassignment procedures being performed on children despite evidence of harms and a lack of evidence of benefits.

A stronger definition of medical necessity is required. In the context of medical interventions that alter, or are intended to alter, sex characteristics, we propose that an intervention is ‘medically necessary’ if it is:

- (a) urgently required, such that the intervention cannot be delayed until a minor has the capacity to express a view or provide their own informed consent, due to the immediate or near-immediate and grave health risks posed by such delay; and
- (b) not a medical emergency; and
- (c) therapeutic, such that 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.⁶⁷

In other words, an intervention may be therapeutic, but unless urgent, it is not medically necessary, and medically necessary interventions should be distinguished from medical emergencies. Medical emergencies require life-saving intervention or treatment to prevent significant pain and distress, or serious damage to a person’s health, as a matter of urgency, and in those situations medical professionals are able to intervene without the consent of the individual or their parents or guardians.⁶⁸

⁶⁶ *Marion’s Case* (1992) 175 CLR 218, 274 (Brennan J). For discussion, see: *Re Kelvin* (2017) 351 ALR 329, 349-51 (Thackray, Strickland, and Murphy JJ).

⁶⁷ As defined by Brennan in *Marion’s Case*. *Marion’s Case* (1992) 175 CLR 218, 269 (Brennan J). Although Brennan J dissented in *Marion’s Case*, his Honour’s views concerning the distinction between therapeutic and non-therapeutic procedures was not in dissent. See: *Re Kelvin* (2017) 351 ALR 329, 349 at 132 (Thackray, Strickland, and Murphy JJ).

⁶⁸ See e.g. *Medical Treatment Planning and Decisions Act 2016* (Vic) s53.

In the absence of medical necessity, that an intervention conveys health benefits (i.e. that it is therapeutic) is not sufficient justification for overriding an individual's bodily autonomy and the need to obtain their consent. The intervention must also be non-deferrable (i.e. urgently required), such that to defer the intervention would result in immediate or near-immediate and grave health consequences.

The element of urgency is not a new concept. In *Marion's Case*, for example, McHugh J noted as follows:

[i]f there is any real possibility that, at some future time, the child will acquire the capacity and maturity to choose whether he or she should be sterilised, the carrying out of that procedure cannot be in the best interests of the child unless, of course, protection of the child's health *urgently* requires that the procedure be carried out during incompetency.⁶⁹

The joint judgment (Mason CJ, Dawson, Toohey and Gaudron JJ) also recognised the need to consider temporal factors, that is, whether the child *will ever* be capable of giving or refusing informed consent.⁷⁰ Similarly, the *Family Law Rules 2004* (Cth) require that for medical procedure applications, in circumstances where the child is incapable of making an informed decision, evidence is to be adduced that the child is 'unlikely to develop sufficiently to be able to make an informed decision *within the time* in which the procedure should be carried out, or *within the foreseeable future*'.⁷¹ Despite such references to temporal considerations, difficulties arise in practice because they are not afforded enough weight, especially regarding the question of the urgency, or non-deferability, of the relevant procedure in the unique context of procedures that alter, or are intended to alter, sex characteristics. Kelly and Smith have asserted, for example, that Forrest J failed to give such issues detailed consideration in *Re Carla* (2016) 54 Fam LR 576.⁷² Consequently, the definition of medical necessity proposed expressly emphasises the issue of urgency.

It should be clear that according to the proposed definition of medically necessary interventions, all instances of sex reassignment of intersex children are medically unnecessary. By comparison, interventions such as the surgical closing of open wounds, correction of urinary tract obstructions, or creation of an outlet for menstruation, are medically necessary. Importantly, an intervention that may be necessary in the future for an infant or child should be undertaken when it becomes necessary, and should not be pre-empted prior to that point in time.

11.3. Prohibition

All medically unnecessary interventions that alter, or are intended to alter, sex characteristics that are performed on an individual without their own informed consent, or without their clearly expressing a view for such interventions to occur with subsequent approval of a tribunal or court, should be prohibited by law.

⁶⁹ *Marion's Case* (1992) 175 CLR 218, 320 (McHugh J) (emphasis added), although his Honour was in dissent regarding the issue of the ability of the parents to consent to the procedure, his Honour agreed as to the jurisdiction of the Family Court to authorise the procedure.

⁷⁰ *Marion's Case* (1992) 175 CLR 218, 236 - 237 (emphasis added).

⁷¹ *Family Law Rules 2004* (Cth), Chapter 4, Part 4.2, Division 4.2.3, r 4.09 (emphasis added).

⁷² Kelly, F. and Smith, M.K. (2017). Should court authorisation be required for surgery on intersex children? A critique of the Family Court decision in *Re Carla*. *Australian Journal of Family Law*, 31(2):118-133, pp.131 - 132.

Similar procedures on non-intersex girls and women are already criminalised as female genital mutilation in every state and territory.⁷³ In Victoria, it is even illegal for consenting adult women to have such cosmetic procedures,⁷⁴ although to our knowledge this law has never been enforced.

In principle, in the absence of medical necessity, interventions that alter, or are intended to alter, sex characteristics should be criminalised when performed without an individual having provided their own informed consent, or having expressed a view and obtained tribunal or court approval, for such interventions to be performed. *In practice*, however, there is a need for any proposed legislation to be limited to people born with intersex variations. Moreover, *in practice*, criminalisation of interventions on people born with variations in sex characteristics is complicated by political realities, namely that while waning, there is still support among some quarters of the medical profession when it comes to medically unnecessary interventions that alter the sex characteristics of intersex children; Moreover, as most parents want what is best for their children, and are simply following the advice of doctors, it would be unfair for any law to criminalise their acting on that medical advice, however bad that advice might be.

In short, until cultural change occurs within the medical profession, making medically unnecessary interventions on non-consenting individuals a civil offence represents a good incremental reform, as it would signal to the medical profession, and wider community, that such practices are unacceptable.

The law's recognition of the spectrum of natural variations in sex characteristics would also have an enfranchising function. In failing to protect or address the needs of intersex people, the law effectively legitimises informal medical narratives that attempt to 'normalise' intersex bodies through unnecessary medical interventions.

Recommendation 8

Immediately following the development of standards of care for intersex people, enact legislation to prohibit medically unnecessary interventions that alter, or are intended to alter, the sex characteristics of non-consenting individuals.

12. Education, support & advocacy

Narrow clinical perspectives about intersex variations have an authoritative character that often imply interventions are medically necessary when in fact they are not. The medical pathologisation of otherwise healthy people with intersex variations fosters and maintains significant stigma, shame, and discrimination. Faced with a lack of support to guide and emotionally process diagnosis with an intersex variation, intersex people and their families are often forced into secrecy, electing to conceal the diagnosis and pursue unnecessary and invasive medical interventions. This further isolates intersex people and their families, and precludes them from making fully informed decisions about interventions that can cause lasting and irreversible bodily harm. There remains little integrated health, psychological, and

⁷³ *Crimes Act 1900* (NSW) s45; *Crimes Act 1958* (Vic) ss32-34A; *Criminal Code Act 1899* (Qld) s323A; *Criminal Code Act 1924* (Tas) s178A; *Criminal Law Consolidation Act 1935* (SA) s33A; *Crimes Act 1900* (ACT) s74; *Criminal Code Act* (NT) 186B; *Criminal Code Act Compilation Act 1913* (WA) s306.

⁷⁴ *Crimes Act 1958* (Vic) s34.

peer-based support for intersex people, caregivers, and families, and a lack of awareness of intersex variations and issues amongst the population in general as well as medical professionals in particular.

12.1. Education

Intersex peer and advocacy organisations play an essential role in combating discriminatory attitudes that arise from misinformation, and empowering intersex people to make informed decisions about their own lives. However, intersex organisations are unfunded and therefore have limited capacity to advocate on behalf of intersex people and provide peer-based education and support services. As a result, sources of information and education about the experiences of people born with variations in sex characteristics provided to intersex individuals and parents of intersex children, is largely limited to advice conveyed by medical professionals. Although some may find useful information created by intersex organisations online, it would seem many are not referred to such information by medical professionals. Indeed, intersex people who have been subjected to medical interventions have conveyed mistrust of the medical profession and reported disappointment with the lack of information provided to them about their intersex variations.⁷⁵ To improve on this situation, ongoing training for medical professionals that work with intersex people is required.

Recommendation 9

Fund intersex organisations to advocate on behalf of intersex people, and to provide peer-based education and support services to parents of intersex children and medical professionals.

Recommendation 10

Fund the training of all health professionals that work with intersex people on the health needs and human rights of intersex people.

12.2. Peer support

The *Darlington Statement* has identified the importance of independent peer-based support, capable of affirming the broad diversity of intersex experiences, and supporting intersex people in their day-to-day lives.⁷⁶ Support groups that are directly affiliated with prominent medical organisations or members risk being dominated by singular, often clinical, narratives about the 'correct' or 'best' approach to treating a specific intersex variation. This has the inadvertent effect of further stigmatising and isolating intersex people and their families, particularly if past and present medical decisions do not conform to what is considered 'common or preferred practice'.

Independent peer-led groups and psychological support services that are affirmative and inclusive are essential to guiding individuals and families through what can be a stressful and uncertain time in their lives. Intersex people and their families must be given space to connect with and share experiences with similarly situated people in order to make fully informed decisions. Sharing those experiences in affirmative and inclusive spaces is

⁷⁵ Community Affairs References Committee. (2013). (n.7). para 2.36.

⁷⁶ Darlington Statement. (March 2017). (n.41).

psychologically liberating, and capable of normalising and validating struggles that may feel individually insurmountable.

Recommendation 11

Fund independent and affirmative peer-based support groups that are inclusive and open to all individuals with intersex variations.

13. Conclusion

Difference is not a defect. While some intersex variations result in the need for certain medical interventions, many do not. Despite this, most intersex people currently undergo invasive and irreversible procedures as non-consenting minors to alter their sex characteristics, including ‘normalising’ sex reassignment surgery and hormone interventions. These interventions can cause significant physical and psychological harm.

Medically unnecessary interventions are non-urgent, and as such can be deferred. If an individual is too young to provide informed consent to a medically unnecessary intervention, then that intervention should be deferred until they’re old enough to do so, or until they are old enough to express a view for such interventions to be performed and obtain approval by a tribunal or court.

The only surgical interventions that are medically necessary are those that are urgent and required to correct dysfunction that can result in bodily harm, such as urinary tract obstructions, the closing of open wounds, or the creation of an outlet for menstruation. Likewise, hormone interventions should be restricted to cases that prevent or treat illness. Surgery and hormone interventions should not be used solely for the purposes of masculinising or feminizing children who have not consented to their sex characteristics being changed. An intervention that may be necessary in the future for an infant or child should be undertaken when it becomes necessary, and not prior to that point in time.

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child must be a paramount consideration. States Parties to the Convention on the Rights of the Child undertake to ensure the child such protection and care as is necessary for their wellbeing, taking into account the rights and duties of their parents, legal guardians, or other individuals legally responsible for them, and, to this end, must take all appropriate legislative and administrative measures.⁷⁷ Standards of care for intersex people are an administrative measure for their protection, and a legislative measure would be the prohibition of non-consensual, medically unnecessary interventions that alter sex characteristics.

Standards of care for intersex people must be consistent with international human rights law, and be developed by human rights experts, child advocates, medical ethicists, child psychologists, medical doctors, and people with lived experience of intersex variations. To ensure the standards of care are enforced, they should be supported by the establishment of a special decision-making and review tribunal that also includes people with such areas of

⁷⁷ Convention on the Rights of the Child, Article 3(2).

expertise. Importantly, the standards of care must incorporate a definition of ‘medically necessary’ interventions, establish medical necessity as the test for whether a particular medical intervention for a particular intersex variation at a particular time is acceptable, and prioritise the consent of the individual to be subject to medically unnecessary interventions over that of their parents or caregivers.

While *in principle* medically unnecessary interventions that alter, or are intended to alter, the sex characteristics of non-consenting individuals should be criminalised for everyone, as it already is for non-intersex girls and women, *in practice* cultural change within the medical profession must come first if this is to occur for people born with intersex variations. As an interim step, standards of care for intersex people should be developed, and immediately following their development, legislation should be enacted to establish a decision-making and review tribunal to ensure the standards of care are adhered to, and to in effect, prohibit medically unnecessary interventions that alter the sex characteristics of non-consenting individuals.

Inclusive, affirmative, and independent support services provide a means for positive cultural change. Misinformation, stereotypes, and incoherent understandings of intersex variations, rather than malicious intent, often underpin the practice of non-consensual medical interventions. Intersex advocacy organisations are in the best position to inform the direction of educational initiatives, and must be adequately funded in order to do so. Medical professionals, who are usually the first-point of contact at the time of the intersex diagnosis, must also receive appropriate training to advise individuals and families in a manner that *facilitates* free and fully-informed decision-making. Networks of independent peer-led groups and psychological services are a key counter-balance to clinical institutions, and should be resourced to support intersex people and their families.