

## Intersex Human Rights Australia Ltd For intersex human rights, information, and education

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# Submission to the Australian Law Reform Commission on the Review of the Family Law System – Issues Paper

### 1 Introduction

We thank the Australian Law Reform Commission for the opportunity to make a submission on the *Review of the Family Law System—Issues Paper*.

Intersex Human Rights Australia (IHRA) is a national intersex-led organisation that promotes the human rights (including the bodily autonomy) of people born with intersex variations. Formerly known as Organisation Intersex International (OII) Australia, IHRA is a not-for-profit company, with Public Benevolent Institution (charitable) status: <a href="http://ihra.org.au">http://ihra.org.au</a>. This submission is endorsed by:

The Androgen Insensitivity Syndrome Support Group Australia (AISSGA), a peer support, information and advocacy group by and for people affected by androgen insensitivity syndrome (AIS) and/or related intersex variations and variations of sex characteristics, and their families: <a href="http://aissga.org.au">http://aissga.org.au</a>

**Disabled People's Organisations Australia** (DPO Australia) is a national coalition of Disabled People's Organisations, which are run by and for people with disability and grounded in a normative human rights framework: http://www.dpoa.org.au

The **National LGBTI Health Alliance** is the national peak health organisation in Australia for organisations and individuals that provide health-related programs, services and research focused on lesbian, gay, bisexual, transgender, and intersex people (LGBTI) and other sexuality, gender, and bodily diverse people and communities: <a href="http://lgbtihealth.org.au">http://lgbtihealth.org.au</a>

**People with Disability Australia** (PWDA) is a national disability rights and advocacy organisation, and member of DPO Australia. PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also have a large associate membership: <a href="http://pwd.org.au">http://pwd.org.au</a>

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### 3 Intersex

IHRA refers to intersex people in this document in line with a definition given in 2016 by the UN Office of the High Commissioner for Human Rights, African Commission on Human and Peoples' Rights, Council of Europe Commissioner for Human Rights and Inter-American Commission on Human Rights:

Intersex people are born with physical or biological sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal

patterns) that do not fit the typical definitions for male or female bodies. For some intersex people these traits are apparent at birth, while for others they emerge later in life, often at puberty.<sup>1</sup>

We use this term to include all people born with bodies that do not fit medical or social norms for male or female bodies. In doing so, we acknowledge the diversity of intersex people in terms of our identities, legal sexes assigned at birth, our genders, gender identities, and the words we use to describe our bodies.

Many forms of intersex exist; it is an umbrella term, rather than a single category. At least 30 or 40 different variations are known to science; most are genetically determined. Since 2006, clinicians frequently use a stigmatising label, 'Disorders of Sex Development' or 'DSD', to refer to intersex variations.

Intersex variations can include differences in the number of sex chromosomes, different tissue responses to sex hormones, or a different hormone balance. Examples of intersex variations include androgen insensitivity syndrome (AIS), congenital adrenal hyperplasia (CAH), and sex chromosome differences such as 47,XXY (often diagnosed as Klinefelter syndrome) and 45,X0 (often diagnosed as Turner syndrome). Many persons do not have clear genetic diagnoses.<sup>2</sup> Some common intersex variations are diagnosed prenatally.<sup>3</sup>

### 4 The Issue Paper

The ALRC Issue Paper makes the following statements in relation to intersex people and the family law system, which we respond to in this submission:

90 Transgender and intersex74 children may also be engaged in the family law system in the exercise of the Family Court's welfare jurisdiction relating to approval for medical interventions related to their gender identity.75 Similarly to children with disability who may be subject to the court's welfare jurisdiction, concerns exist about the opportunity for children to participate in this process.76

In our view, this is an unduly narrow framing. Intersex people do not share a singular gender identity; our concern with forced medical interventions is not limited (nor even primarily) in

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<sup>&</sup>lt;sup>1</sup> 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, et al. 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; 2016 [cited 2016 Oct 24]. Available from:

http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E

<sup>&</sup>lt;sup>2</sup> Hiort O. I-03 DSDnet: Formation of an open world-wide network on DSD at clinician conference, "4th I-DSD Symposium"; 2013: 'DSD comprise a heterogeneous group of differences of sex development with at least 40 different entities of which most are genetically determined. An exact diagnosis is lacking in 10 to 80% of the cases', [cited 1 Jul 2013]. Available from <a href="http://www.gla.ac.uk/media/media">http://www.gla.ac.uk/media/media</a> 279274 en.pdf

<sup>&</sup>lt;sup>3</sup> Davis G. The Social Costs of Preempting Intersex Traits. The American Journal of Bioethics. 2013;13(10):51–3.

relation to gender identity. Intersex issues should not be constrained by a gender identity lens, nor an LGBT lens.

Our concerns go far beyond the extent to which minors are able to participate in legal proceedings. It may be helpful for the Commission to note that the 2013 amendment to the Sex Discrimination Act enacted multiple new attributes in law: 'intersex status' as well as 'gender identity',<sup>4</sup> precisely because intersex is a distinct concept.

### The welfare jurisdiction

134 Concerns have also been raised about the Family Law Act's welfare jurisdiction, which gives the family courts a broad power to make orders relating to the welfare of children.145 This supervisory jurisdiction of the court is used to support a range of orders arising outside the context of a dispute between parents, although the scope of the court's power under s 67ZC is uncertain.146 Recent reports and early consultations have revealed concerns about how the welfare jurisdiction operates in relation to people with disability (in particular in relation to the sterilisation of young women), and in relation to intersex children.

135 The sterilisation of a young person, including one with an intellectual disability, must usually be authorised by the Family Court pursuant to the exercise of its welfare jurisdiction.147 Scholarly critiques have suggested that, in these matters, the Court has tended to focus on the person's disability, including assumptions about their lack of capacity, instead of looking at their social context and capabilities.148 Organisations such as Women with Disabilities Australia and the Australian Human Rights Commission have argued that forced sterilisation is a serious violation of human rights, and have called for a prohibition of the involuntary or coerced sterilisation of girls unless there is a serious threat to life.149 However, the Family Court has noted that it is increasingly rare for such applications to be brought.150 In 2013, the Senate Standing Committee on Community Affairs recommended the development of uniform model legislation to regulate the sterilisation of people with disability.151

136 In relation to intersex children, concerns have been raised about the ability of intersex children to participate in decision making about their gender identity and the extent to which court scrutiny on decisions in relation to medical treatment is required to uphold human rights standards. In Re: Carla,152 the court held that its prior consent to the removal of gonads in a five year old child who was raised as a girl having been born with 'the external appearance of a girl, but with male gonads not contained within a scrotum' was not required.153 This approach has been criticised by human rights advocates, on the basis that significant risks can ensue from the treatment, including infertility and loss of sexual sensation.154 Intersex people have reported that it is common for medical procedures to be carried out on infants or young children, without their consent.155 Responding to concerns from intersex organisations, the Senate Community Affairs Reference

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<sup>&</sup>lt;sup>4</sup> Australia. Sex Discrimination Act 1984 [Internet]. Jun 18, 2015. Available from: <a href="https://www.comlaw.gov.au/Details/C2015C00275/Download">https://www.comlaw.gov.au/Details/C2015C00275/Download</a>

Committee in 2013 recommended that all proposed intersex medical interventions for children and adults without the capacity to consent should require authorisation from a civil and administrative tribunal or the Family Court.156

This paragraph more accurately captures key concerns for intersex human rights defender and other human rights advocates. The immediate issue is the failure of the Family Court to properly exercise the protective jurisdiction in its responsibility to monitor and scrutinise invasive, permanent, irreversible and non-therapeutic medical interventions. In *Re Carla (Medical procedure)*, for example, the relevant so-called 'normalising' medical interventions extended far beyond the sterilising gonadectomy which was the focus of the proceedings. Other deeply invasive and permanent interventions such as hormone therapy and genital surgeries performed without court approval were noted by the judge without adverse comment. Consequential issues include the provision of alternative, effective means to protect infants and children from unnecessary medical interventions, the provision of effective, lightweight oversight for medical procedures, access to resourced peer support, and the adoption of appropriate standards of care.

### 5 Human rights and the principles we apply in this submission

Current clinical practices in Australia include a range of medical interventions that are recognised to be forced and coercive, and forms of ill-treatment; they contravene Australia's human rights obligations under the International Covenant on Civil and Political Rights (ICCPR), the Convention on the Rights of the Child (CRC),<sup>5</sup> the Convention against Torture (CAT),<sup>6</sup> and the Convention on the Rights of Persons with Disabilities (CRPD).<sup>7</sup>

### 5.1 UN Human Rights Committee observations

In late 2017, the UN Human Rights Committee responded to concerns raised about practices in Australia, made in a submission by IHRA endorsed by the AIS Support Group Australia, Disabled People's Organisations of Australia, National LGBTI Health Alliance, and People

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<sup>&</sup>lt;sup>5</sup> Attorney General's Department. Australia's joint fifth and sixth report under the Convention on the Rights of the Child, second report on the Optional Protocol on the sale of children, child prostitution and child pornography and second report on the Optional Protocol on the involvement of children in armed conflict. 2018 Jan. Report No.: INT/CRC/ADR/AUS/29898/E.

<sup>&</sup>lt;sup>6</sup> Carpenter M, Organisation Intersex International Australia. Contribution to the List of Issues Prior to Reporting to the Committee against Torture for Australia. Sydney: Organisation Intersex International Australia; 2016 Jun [cited 2018 Mar 30]. Available from: <a href="https://ihra.org.au/30546/loi-cat-review/">https://ihra.org.au/30546/loi-cat-review/</a> Committee against Torture. List of issues prior to submission of the sixth periodic report of Australia. Geneva: United Nations; 2017 Jan. Report No.: CAT/C/AUS/QPR/6.

<sup>&</sup>lt;sup>7</sup> Carpenter M, Organisation Intersex International Australia. Shadow Report submission to the Committee on the Rights of Persons with Disabilities on the situation of intersex people in Australia. 2017 Jun [cited 2018 Mar 30]. Report No.: INT/CRPD/ICS/AUS/28302. Available from: <a href="https://ihra.org.au/31467/submission-crpd-2017/">https://ihra.org.au/31467/submission-crpd-2017/</a> Committee on the Rights of Persons with Disabilities. List of issues prior to the submission of the combined second and third periodic reports of Australia. Geneva: United Nations; 2017 Sep. Report No.: CRPD/C/AUS/QPR/2-3.

with Disability Australia.<sup>8</sup> The response cited ICCPR Treaty articles on non-discrimination (articles 3 and 24), protection from torture and experimentation (article 7), the right to liberty and security (article 9), privacy (article 17), and equality before the law (article 26).<sup>9</sup> These citations highlight the many ways in which current medical practices in Queensland and elsewhere in Australia violate our human rights:

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

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

### 5.2 Protecting bodily integrity

Two key documents guide our thinking on protecting the bodily integrity of infants, children and adolescents: the *Darlington Statement*, and the *Yogyakarta Principles plus 10*.

### **5.2.1** The Darlington Statement

The *Darlington Statement* is a community consensus statement by Australian and Aotearoa/New Zealand intersex organisations and advocates, signed in March 2017.<sup>10</sup> It provides a statement about our heterogeneity, acknowledging:

- 3. The **diversity of our sex characteristics** and bodies, our identities, sexes, genders, and lived experiences. We also acknowledge **intersectionalities** with other populations, including same-sex attracted people, trans and gender diverse people, people with disabilities, women, men, and Indigenous Aboriginal and Torres Strait Islander, Tangata Whenua and racialised, migrant and refugee populations.
- 4. That the word 'intersex', and the intersex human rights movement, **belong equally to all people born with variations of sex characteristics**, irrespective of our gender identities, genders, legal sex classifications and sexual orientations.

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<sup>&</sup>lt;sup>8</sup> Carpenter M, Organisation Intersex International Australia. Shadow Report submission to the Human Rights Committee on the situation of intersex people in Australia. 2017 Aug [cited 2018 Mar 30]. Report No.: INT/CCPR/CSS/AUS/28771. Available from: <a href="https://ihra.org.au/31568/shadow-report-iccpr-2017/">https://ihra.org.au/31568/shadow-report-iccpr-2017/</a>

<sup>&</sup>lt;sup>9</sup> Human Rights Committee. Concluding observations on the sixth periodic report of Australia. 2017 Dec. Report No.: CCPR/C/AUS/CO/6.

Androgen Insensitivity Syndrome Support Group Australia, Intersex Trust Aotearoa New Zealand, Organisation Intersex International Australia, Black E, Bond K, Briffa T, et al. Darlington Statement. Sydney, NSW; 2017 Mar. Available from: <a href="http://darlington.org.au/statement/">http://darlington.org.au/statement/</a>

We respectfully request that the Australian Law Reform Commission respect this heterogeneity and, *inter alia*, not incorrectly presume that intersex people share a singular gender identity. Nor should the concerns of intersex people be restricted to an LGBT lens. We further discuss these issues later.

The Darlington Statement identifies our core human rights concerns as including:

5. Our rights to **bodily integrity, physical autonomy and self determination**.

Key relevant concerns identified in the Statement are:

- 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.

Relevant consequential demands include:

7. We call for the immediate **prohibition as a criminal act** of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent. We call for freely-given and fully informed consent by individuals, with individuals and families having mandatory independent access to funded counselling and peer support.

Paragraph 7 seeks to address a question of necessity by focusing on whether or not it is possible to defer a procedure on a child until they are old enough to provide informed consent, supported by access to peers.

9. We call for **effective legislative protection** from discrimination and harmful practices on grounds of **sex characteristics**.

'Sex characteristics' is proposed in place of 'intersex status' in anti-discrimination law.

- 17. We call for the implementation of advisory bodies to develop appropriate **human rights-based, lifetime, intersex standards of care** with full and meaningful participation by intersex community representatives and human rights institutions.
- 21. We call for the provision of alternative, independent, effective human rights-based oversight mechanism(s) to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations. The pros and cons for and against medical treatment must be properly ventilated and considered, including the lifetime health, legal, ethical, sexual and human rights implications.

Standards of care and oversight are required to tackle cases where non-deferrable medical necessity is asserted, and where informed consent to irreversible procedures to modify the sex characteristics of minors is asserted. Standards of care and oversight need to address lifelong health issues, including health issues consequential to early medical interventions. The composition of bodies providing oversight is proposed to be diverse and include interests – including community representation – not addressed in a Family Court setting. This demand provides for some flexibility in how it might be met, but guardianship tribunals may be appropriate bodies to facilitate such oversight. Standards of care must affirm the human rights of infants, children and adults and provide benchmarks and standards for medical interventions. Current and historical guidelines and principles have been non-binding and have facilitated human rights violations.

19. We recognise that **intersex people have health and medical needs**, sometimes related to having an intersex variation, and sometimes not. We recognise that for people with an intersex variation, misconceptions and associated stigma can act as barriers to treatment. Current practices are often based on the needs of other populations.

By the latter point, we note that healthcare services for 'LGBTI' populations are often designed around the sexual health needs of adult sexually-active non-heterosexual people, or around the healthcare needs of adults or children intending to transition gender. There are no specialist services for adults with intersex variations, with knowledge of our lifetime health needs including those arising from sterilisations, genital surgeries, or potential cognitive or other health issues.

- 22. We call for **resourced access to necessary and appropriate health, medical and allied services and treatment**, including surgeries and hormone treatment, psychosocial, psychosexual and psychological support, and including reparative treatments. **Standards of care** must support reparative treatments, and must not require conformity with stereotypical and clinical norms for female or male bodies, women and men, nor impose inappropriate psychiatric eligibility assessments.
- 23. Multi-disciplinary teams must operate in line with **transparent, human rights-based standards of care** for the treatment of intersex people and bodies. Multi-disciplinary teams in hospitals must include human rights specialists, child advocates, and independent intersex community representatives.

The *Darlington Statement* is consistent with a global intersex community statement: the 2013 *Malta Declaration*.<sup>11</sup>

### 5.2.2 Yogyakarta Principles and Yogyakarta Principles plus 10

We are also guided by the *Yogyakarta Principles* (2007)<sup>12</sup> and the *Yogyakarta Principles plus* 10 (2017) (the 'new Supplement').<sup>13</sup> The *Principles* are authoritative sets of principles, supplemented in 2017, that apply international human rights law in relation to sexual orientation, gender identity, gender expression and sex characteristics. Australian signatories of the *Yogyakarta Principles plus* 10 include Philip Alston, UN Special Rapporteur on extreme poverty and human rights; Morgan Carpenter, a co-executive director of IHRA; and Chris Sidoti, international human rights specialist and former Australian Human Rights Commissioner (1995-2000).

The new Yogyakarta Principles plus 10 introduce 'sex characteristics' to address the issue that, while fear of non-normative identities is a rationale for medical abuses against intersex people, action to implement protections from violations on grounds of sexual orientation and gender identity have not provided intersex people with protection from the specific violations that we face. It is defined in the following way:

UNDERSTANDING 'sex characteristics' as each person's physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty;

The definition of sex characteristics is not only about intersex people, however. The definition is universal, as everyone has some combination of sex characteristics, whether innate or acquired. Innate intersex characteristics are problematised, leading to violations of the rights to bodily integrity and freedom from torture and experimentation, but not all modifications to sex characteristics are human rights violations. Some might be regarded as cosmetic, or reparative or affirming of a gender or religious identity, when freely chosen.

The term 'sex characteristics' is already used to define intersex and tackle violence and discrimination against intersex bodies, including in Maltese legislation that protects all

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<sup>&</sup>lt;sup>11</sup> Third international intersex forum. Malta Declaration: Public statement by the third international intersex forum [Internet]. Floriana, Malta; 2013 Dec [cited 2018 Mar 30]. Available from: https://ihra.org.au/24241/public-statement-by-the-third-international-intersex-forum/

<sup>&</sup>lt;sup>12</sup> Yogyakarta Principles. The Yogyakarta Principles. Principles on the application of international human rights law in relation to sexual orientation and gender identity. 2007. Available from: <a href="http://www.yogyakartaprinciples.org/principles-en/">http://www.yogyakartaprinciples.org/principles-en/</a>

<sup>&</sup>lt;sup>13</sup> Yogyakarta Principles. 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. 2017. Available from: <a href="http://www.yogyakartaprinciples.org/principles-en/yp10/">http://www.yogyakartaprinciples.org/principles-en/yp10/</a>

children from unconsented and non-urgent modifications to their sex characteristics.<sup>14</sup> This is, broadly, a model we would like to see adopted in Australia.

The UN has also used the term sex characteristics to define intersex as a concept:

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.<sup>1</sup>

Current Australian protections on grounds of intersex status are, in contrast, often incorrectly imputed to offer protections on grounds of identity or legal classification. In reality, the attribute of 'intersex status' refers to 'physical features', a purely biological definition, which makes no reference to sex classification, gender identity or sexual orientation. The attribute of 'intersex status' is also, at the same time, based on a model of deficit (of what intersex people may lack), and also broad enough to include many acquired characteristics as well as innate characteristics (so as to avoid the introduction of a bona fide test). The universal attribute of 'sex characteristics' avoids imputations of a relationship to a specific identity, and it is not grounded in a model of deficit.

The new Supplement also recognises that the grounds of sexual orientation, gender identity, gender expression and sex characteristics are themselves intersectional. It recognises the distinct needs, characteristics and human rights situations of individuals and populations of diverse sexual orientations, gender identities, gender expressions and sex characteristics. It thus recognises that intersex people have distinct needs, characteristics and situations compared to lesbians, gay men, bisexual people and transgender people. Principles on protecting bodily integrity and the right to truth tackle issues with the 'best interests' test and partial or non-disclosure of clinical and social information.

#### **5.2.3** Best interests

The Family Law Act 'Section 60B Objects of Part and principles underlying it' aims to ensure the best interests of the child are met my ensuring meaningful involvement of children in decision making (a principle referenced in the Issue Paper) but also 'protecting children from physical or psychological harm from being subjected to, or exposed to, abuse, neglect or family violence'. It also gives effect to the Convention on the Rights of the Child.

Principle 18 of the 2007 *Yogyakarta Principles* adopts the same principles in a call for protection from medical abuses to impose a gender identity:

<sup>&</sup>lt;sup>14</sup> Malta. Gender Identity, Gender Expression and Sex Characteristics Act: Final version. Mar, 2015. Available from: <a href="http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1">http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=26805&l=1</a>

 $<sup>^{15}</sup>$  Australia, Parliament, ComLaw. Sex Discrimination Act 1984. Jun 18, 2015. Available

from: https://www.comlaw.gov.au/Details/C2015C00275/Download

<sup>&</sup>lt;sup>16</sup> Commonwealth of Australia. Family Law Act 1975 - Sect 60B Objects of Part and principles underlying it [Internet]. Available from: <a href="http://www8.austlii.edu.au/cgi-">http://www8.austlii.edu.au/cgi-</a>

bin/viewdoc/au/legis/cth/consol act/fla1975114/s60b.html?context=1;query=convention%20on%20the%20ri ghts%20of%20the%20child;mask path=au/legis/cth/consol act/fla1975114

[States shall] b) Take all necessary legislative, administrative and other measures to ensure that no child's body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration;

However, determinations of children's best interests in relation to medical interventions on intersex bodies do not meet these statements. Yogyakarta Principles Principle 18 has proven inadequate as a result. Indeed, as the UN Committee on the Rights of the Child has pointed out in the years since the Yoqyakarta Principles were first adopted, the best interests principle can (and has been) manipulated to justify violations of the right to bodily integrity. Committee on the Rights of the Child. General Comment 14 'on the right of the child to have his or her best interests taken as a primary consideration' states:

34. The flexibility of the concept of the child's best interests allows it to be responsive to the situation of individual children and to evolve knowledge about child development. However, it may also leave room for manipulation; the concept of the child's best interests has been abused by Governments and other State authorities to justify racist policies<sup>17</sup>

Committee on the Rights of the Child General Comment 13 on 'Article 19: The right of the child to freedom from all forms of violence' states that interpretations of best interests 'cannot be used to justify practices ... which conflict with the child's human dignity and right to physical integrity':

54. Article 3 (Best interests of the child): The Committee emphasizes that the interpretation of a child's best interests must be consistent with the whole Convention, including the obligation to protect children from all forms of violence. It cannot be used to justify practices, including corporal punishment and other forms of cruel or degrading punishment, which conflict with the child's human dignity and right to physical integrity. An adult's judgment of a child's best interests cannot override the obligation to respect all the child's rights under the Convention. 18

The UN Committee on Civil and Political Rights identified in General Comment 35 that the right to bodily integrity is derived from article 3 of the Universal Declaration of Human Rights; the right to life, liberty and security of the person:

2. Article 9 recognizes and protects both liberty of person and security of person. In the Universal Declaration of Human Rights, article 3 proclaims that everyone

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<sup>&</sup>lt;sup>17</sup> Committee on the Rights of the Child. General Comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1). 2013. Report No.: CRC/C/GC/14, para. 34. Available from: http://undocs.org/CRC/C/GC/14

<sup>&</sup>lt;sup>18</sup> Committee on the Rights of the Child. General Comment 13: Article 19: The right of the child to freedom from all forms of violence. 2011. Report No.: CRC/C/GC/13, para. 54. Available from: <a href="http://undocs.org/CRC/C/GC/13">http://undocs.org/CRC/C/GC/13</a>

has the right to life, liberty and security of person. That is the first substantive right protected by the Universal Declaration, which indicates the profound importance of article 9 of the Covenant both for individuals and for society as a whole...

3. ... Security of person concerns freedom from injury to the body and the mind, or bodily and mental integrity...<sup>19</sup>

#### 5.2.4 Principle 32: The Right to Bodily and Mental Integrity

The Yogyakarta Principles plus 10 address concerns regarding the best interests test. Principle 32 on the right to bodily and mental integrity recognises that forced and coercive medical practices violate human rights principles on freedom from torture, cruel, inhuman and degrading treatment – a principle which includes freedom from experimental treatment. Such practices also violate to the right to bodily integrity, a right that derives from the right to security. The principle requires free prior and informed consent except in situations of urgent necessity for medical treatment. It calls on governments to combat the stigma and stereotypes that underpin treatment. Principle 32, 'The Right to Bodily and Mental Integrity' (YP+10) states:

Everyone has the right to bodily and mental integrity, autonomy and self-determination irrespective of sexual orientation, gender identity, gender expression or sex characteristics. Everyone has the right to be free from torture and cruel, inhuman and degrading treatment or punishment on the basis of sexual orientation, gender identity, gender expression and sex characteristics. No one shall be subjected to invasive or irreversible medical procedures that modify sex characteristics without their free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm to the concerned person.

### States shall:

- A) Guarantee and protect the rights of everyone, including all children, to bodily and mental integrity, autonomy and self-determination;
- B) Ensure that legislation protects everyone, including all children, from all forms of forced, coercive or otherwise involuntary modification of their sex characteristics;
- C) Take measures to address stigma, discrimination and stereotypes based on sex and gender, and combat the use of such stereotypes, as well as marriage prospects and other social, religious and cultural rationales, to justify modifications to sex characteristics, including of children;
- 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;

<sup>&</sup>lt;sup>19</sup> Committee on Civil and Political Rights. General Comment No. 35: Article 9 (Liberty and security of person). 2014 Dec. Report No.: CCPR/C/GC/35.

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;

F) Provide adequate, independent counselling and support to victims of violations, their families and communities, to enable victims to exercise and affirm rights to bodily and mental integrity, autonomy and self-determination;

G) Prohibit the use of anal and genital examinations in legal and administrative proceedings and criminal prosecutions unless required by law, as relevant, reasonable, and necessary for a legitimate purpose.

#### 5.2.5 A policy of concealment

Medical practices have historically – and may still currently – be grounded in a model of concealment. In 1998, Cheryl Chase discussed what Kipnis and Diamond consider an 'epistemological black hole' that Chase notes 'precludes follow-up of intersex surgeries':

the purpose of surgery is to hide intersexuality, therefore intersexuals must be lied to about their histories and surgeries, and thus follow-up cannot be done because the patients would learn the truth.<sup>20</sup>

In 2018, the New Zealand Office of the Privacy Commissioner stated:

The recommended medical approach in the latter half of the twentieth century was to treat patients with 'normalisation' procedures, including surgery, and to raise the individual according to their normalised sex, often without providing full information to the patient as they grew up.

Over the past 15-20 years, leading health professionals internationally have advocated for talking with children and young people in age- appropriate ways about their diagnosis and any treatment they might have had. The extent to which this more open practice has been taken up in New Zealand seems to be variable, so some people will have grown up knowing about their diagnosis and treatment, while others will not.<sup>21</sup>

Australia and New Zealand share medical and clinical associations, and the same variability in current practices is likely here also. Additionally, individuals who exited the paediatric hospital system at age 18 during the existence of current or historic policies of concealment may remain unaware of the nature of medical interventions that they have experienced.

#### 5.2.6 Partial information disclosure

Parents may also be told skewed and partial information about their child in ways that have a direct impact on the medical interventions experienced by their child. Streuli and others, for example, have identified how:

<sup>&</sup>lt;sup>20</sup> Chase C. Surgical Progress Is Not the Answer to Intersexuality. Journal of Clinical Ethics. 1998;9(4):385–92.

<sup>&</sup>lt;sup>21</sup> Blackwood V, Office of the Privacy Commissioner. Handling health information of intersex individuals [Internet]. Office of the Privacy Commissioner. 2018 [cited 2018 Mar 7]. Available from: <a href="https://www.privacy.org.nz/blog/handling-health-information-of-intersex-individuals/">https://www.privacy.org.nz/blog/handling-health-information-of-intersex-individuals/</a>

Parental decisions concerning early sex assignment surgery for DSD children depend on the health professional counseling received, to a degree of which neither parents nor professionals appear fully aware. In the absence of conclusive data for or against early surgery, there is a danger of medicalized or demedicalized parentalism resulting in irreversible and inadequately grounded decisions.<sup>22</sup>

Furthermore, silence and secrecy means that there is no longitudinal research underpinning irreversible clinical practices, their necessity, indications, timing or even evaluation.

Current protocols, set out in a 2006 Chicago 'Consensus statement on management of intersex disorders' suggested that: 'Appearance-altering surgery is not urgent' yet, at the same time, it states explicit rationales for 'early reconstruction' including 'minimizing family concern and distress' and 'mitigating the risks of stigmatization and gender-identity confusion'.<sup>23</sup>

Clinicians and parents may make decisions based upon delivery room distress,<sup>24</sup> and social and cultural bias. Julie Greenberg states that:

safeguards are needed because parents may be making decisions at a time when they are suffering distress about giving birth to and raising an "abnormal" child. Under these circumstances, it is difficult for parents to objectively determine the treatment that would be in their child's long term best interests, especially because the issue may affect sexuality when the child becomes an adult.<sup>25</sup>

In a clinical study of parents of intersex children, Dayner, Lee and Houk surveyed the perspectives of 21 parents of 17 children with XX sex chromosomes and congenital adrenal hyperplasia, finding that 100% of parents agreed surgery was 'done for more "natural looking" genitalia', and 95% 'would consent to surgery if adult sexual sensation reduced'. However, Liao et al report that 'parental regret can be high', and parents 'may not realise that they are de facto opting for experimental surgery on their children', with no credible non-surgical treatment pathways. In 2016, a co-author of that editorial stated in a clinical conference abstract:

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<sup>&</sup>lt;sup>22</sup> Streuli JC, Vayena E, Cavicchia-Balmer Y, Huber J. Shaping Parents: Impact of Contrasting Professional Counseling on Parents' Decision Making for Children with Disorders of Sex Development: Parent Decision in Disorders of Sex Development. The Journal of Sexual Medicine. 2013 Aug;10(8):1953–60.

<sup>&</sup>lt;sup>23</sup> Houk CP, Hughes IA, Ahmed SF, Lee PA, Writing Committee for the International Intersex Consensus Conference Participants. Summary of Consensus Statement on Intersex Disorders and Their Management. PEDIATRICS. 2006;118(2):753–7.

<sup>&</sup>lt;sup>24</sup> Department of Health and Human Services. Ambiguous genitalia in neonates [Internet]. 2015 [cited 2017 Apr 2]. Available from: <a href="https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/congenital-abnormalities/ambiguous-genitalia">https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/congenital-abnormalities/ambiguous-genitalia</a>

<sup>&</sup>lt;sup>25</sup> Greenberg JA. Intersexuality and the Law: Why Sex Matters. New York: New York University Press; 2012.

<sup>&</sup>lt;sup>26</sup> Dayner JE, Lee PA, Houk CP. Medical Treatment of Intersex: Parental Perspectives. Journal of Urology. 2004;172(4):1762–5.

<sup>&</sup>lt;sup>27</sup> Liao L-M, Wood D, Creighton SM. Parental choice on normalising cosmetic genital surgery. BMJ. 2015;351:h5124.

Many multidisciplinary teams are led by surgeons committed to genital surgery. In addition complex invasive surgery may be reimbursed at high tariffs for health care providers. Psychological support – although less costly – is often patchy or unavailable...

Credible non-surgical pathways with ongoing psychological support for the family currently do not exist.<sup>28</sup>

We note from clinical literature published in 2016 that there remains no clinical consensus regarding indications, timing, procedure or evaluation of surgical interventions to 'normalise' intersex bodies. A 'Global Disorders of Sex Development Update since 2006' states regarding genital surgeries:

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 ... Timing, choice of the individual and irreversibility of surgical procedures are sources of concerns. There is no evidence regarding the impact of surgically treated or non-treated DSDs during childhood for the individual, the parents, society or the risk of stigmatization.<sup>29</sup>

In 2017, the Committee on Bioethics of the Council of Europe commissioned a report examining the rights of children in biomedicine. The report authors made extensive comments and citations, including citing clinical literature showing that:

(1) "quality of life" studies on patients into adulthood are lacking and are "poorly researched", (2) the overall impact on the sexual function on children surgically altered is "impaired" and (3) the claim that gender development requires surgery is a "belief" unsubstantiated by data...

On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion<sup>30</sup>

The report of the Committee on Bioethics found that:

• surgery ... in infancy [is done] on the assumption that parental rearing could steer gender development.

<sup>&</sup>lt;sup>28</sup> Creighton S. Surgical Management of DSD: New Insights. 2016 Aug 19 [cited 2016 Aug 31]; Available from: <a href="http://abstracts.eurospe.org/hrp/0086/hrp0086con1.2.htm">http://abstracts.eurospe.org/hrp/0086/hrp0086con1.2.htm</a>

Lee PA, Nordenström A, Houk CP, Ahmed SF, Auchus R, Baratz A, et al. Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care. Hormone Research in Paediatrics. 2016;85(3):158–180.
 Zillén K, Garland J, Slokenberga S, Committee on Bioethics of the Council of Europe. The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties. 2017.

- all evidence-based reviews concur that gender identity and sexual orientation of children with differences in sex development cannot be predicted with accuracy
- the medical literature has not addressed the implications of whether clinicians and parents have a right to assign these identities surgically and irreversibly on children<sup>30</sup>

It stated 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 <sup>30</sup>

Surgeries do not create 'normal' bodies: early surgeries create bodies that need further surgeries due to physical development during adolescence; sterilisations create bodies that have a lifelong need for hormone treatment; scarring creates visible difference; all surgeries affect physical sensitivity.<sup>31</sup>

However, parents and individuals subjected to medical intervention may be unaware that early interventions lack firm evidence and lack clinical consensus. Parents and caregivers may also have no idea that early medical interventions may trigger a lifetime of medical interventions and surgeries.

#### 5.2.7 Experimental treatments

The Committee on Bioethics report states that the lack of scientific evidence in support of medical interventions means that:

children continue to undergo unproven treatments without proof of their therapeutic character <sup>30</sup>

As a consequence, the right to freedom from experimentation is adversely impacted. Additionally, without access to independent peer support, informed consent by parents and informed decision-making by the judiciary is not possible.

We also note similar concern by Kirsten Sandberg, former chair of the Committee on the Rights of the Child, that 'parents have no right to consent to' sex assignment or 'normalising' interventions as 'treatment is not medically necessary' and can be deferred; 'the matter is so personal and serious that treatment should not be carried out without the child's consent'. 32

<sup>&</sup>lt;sup>31</sup> See note 20 and: Australian Senate Community Affairs References Committee. Hearing: Involuntary or coerced sterilisation of people with disabilities in Australia. Thursday 28 March 2013, Hansard [Internet]. Canberra; Mar 28, 2013. Available from: http://www.aph.gov.au/hansard

<sup>&</sup>lt;sup>32</sup> Sandberg K. The Rights of LGBTI Children under the Convention on the Rights of the Child. Nordic Journal of Human Rights. 2015;33(4):337–52.

### 5.2.8 Principle 37: The Right to Truth

This principle of the *Yogyakarta Principles plus 10* builds on rights established to combat impunity, including a right to the truth about individuals' medical histories and access to redress, reparations and restorative treatments; and rights to preserve memory and guarantee the right to know.<sup>33</sup> The Supplement calls for this right to be exempted from statutes of limitations.

### Principle 37, 'The right to truth' states:

Every victim of a human rights violation on the basis of sexual orientation, gender identity, gender expression or sex characteristics has the right to know the truth about the facts, circumstances and reasons why the violation occurred. The right to truth includes effective, independent and impartial investigation to establish the facts, and includes all forms of reparation recognised by international law. The right to truth is not subject to statute of limitations and its application must bear in mind its dual nature as an individual right and the right of the society at large to know the truth about past events.

#### **STATES SHALL:**

- A) Adopt legal provisions to provide redress to victims of violations on the basis of sexual orientation, gender identity, gender expression and sex characteristics, including public apology, expungement of relevant criminal convictions and records, rehabilitation and recovery services, adequate compensation and guarantees of non-recurrence;
- B) Ensure, in cases of violations of the right to mental and bodily integrity, effective access to remedies, redress, reparation and, where appropriate, psychological support and restorative treatments;
- C) Protect individuals' right to know the truth about their medical histories, including through full access to accurate medical records;
- D) Adopt and fully implement procedures to establish the truth concerning violations based on sexual orientation, gender identity, gender expression and sex characteristics;
- E) Establish a truth-seeking mechanism and process in regard to human rights violations based on sexual orientation, gender identity, gender expression and sex characteristics;
- F) Ensure that, in addition to individual victims and their families, communities and society at large can realise the right to the truth about systemic human rights violations based on sexual orientation, gender identity, gender expression and sex characteristics, while respecting and protecting the right to privacy of individuals;

<sup>&</sup>lt;sup>33</sup> Orentlicher D, Economic and Social Council. Report of the independent expert to update the Set of principles to combat impunity, Diane Orentlicher Addendum Updated Set of principles for the protection and promotion of human rights through action to combat impunity. UN Commission on Human Rights; 2005 Feb. Report No.: E/CN.4/2005/102/Add.1.

World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance. Durban Declaration and Programme of Action. 2001, para 98. Available from: <a href="http://www.un.org/WCAR/durban.pdf">http://www.un.org/WCAR/durban.pdf</a>

G) Preserve documentary evidence of human rights violations based on sexual orientation, gender identity, gender expression and sex characteristics, and ensure adequate access to archives with information on violations based on sexual orientation, gender identity, gender expression and sex characteristics; H) Ensure that the facts and truth of the history, causes, nature and consequences of discrimination and violence on grounds of sexual orientation, gender identity, gender expression and sex characteristics are disseminated and added to educational curricula with a view to achieving a comprehensive and objective awareness of past treatment of persons on grounds of sexual orientation, gender identity, gender expression and sex characteristics;

I) Commemorate the suffering of victims of violations on the basis of sexual orientation, gender identity, gender expression and sex characteristics through public events, museums and other social and cultural activities

This Principle has direct relevance to the operation of the family law system in tackling issues relating to the concealment of diagnoses and medical histories, the provision of partial information intended to support specific forms of treatment, non-disclosure of information on lack of evidence and clinical consensus, and non-disclosure of information on peer support and social networks. The Principle also raises systemic issues that affect the ability of parents and prospective parents to understand that infants, children, adolescents and adults born with intersex variations exist.

### 5.3 Sex classifications

In relation to gender identity and sex classifications, the Darlington Statement notes that intersex people do not share a common sex classification or gender identity and makes the following demands:

8. Regarding **sex/gender classifications**, sex and gender binaries are upheld by structural violence. Additionally, attempts to classify intersex people as a third sex/gender do not respect our diversity or right to self determination. These can inflict wide-ranging harm regardless of whether an intersex person identifies with binary legal sex assigned at birth or not.

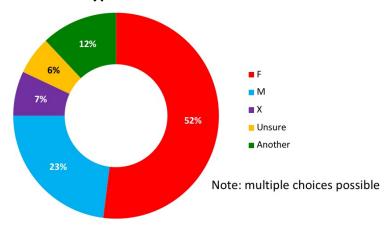
Undue emphasis on how to classify intersex people rather than how we are treated is also a form of structural violence. The larger goal is not to seek new classifications but to **end legal classification systems** and the hierarchies that lie behind them. Therefore:

- a) As with race or religion, sex/gender should not be a legal category on birth certificates or identification documents for anybody.
- b) While sex/gender classifications remain legally required, sex/gender assignments must be regarded as provisional. Given existing social conditions, we do not support the imposition of a third sex classification when births are initially registered.
- c) Recognising that any child may grow up to identify with a different sex/gender, and that the decision about the sex of rearing of an intersex child may have been

- incorrect, sex/gender classifications must be legally correctable through a simple administrative procedure at the request of the individual concerned.
- d) Individuals able to consent should be able to choose between female (F), male (M), non-binary, alternative gender markers, or multiple options.

Indeed, *Darlington Statement* signatories reflect our diversity. Australian sociological research based on a survey of 272 people born with atypical sex characteristics shows that 19% of respondents chose X or other non-binary sex classifications,<sup>34</sup> while 75% choose binary sex classifications. Most intersex people identify with legal sex assigned at birth, while others do not. At the same time, the research found that 60% of participants use the term intersex to describe their sex characteristics.

### Sex of people born with atypical sex characteristics



Jones T. Intersex and Families: Supporting Family Members with Intersex Variations. Journal of Family Strengths. 2017;17(2).

As stated earlier, we respectfully request that the Australian Law Reform Commission respect our heterogeneity as a population and, *inter alia*, not incorrectly presume that intersex people share a singular gender identity. Nor should the concerns of intersex people be restricted to an LGBT lens.

### **6** The Australian policy context

### 6.1 Intertwined therapeutic and non-therapeutic rationales

In 2013, a new attribute of 'intersex status' was added to federal anti-discrimination law, <sup>35</sup> and an inquiry into the involuntary or coerced sterilisation of people with disabilities, and of intersex people, was held by the Senate of Australia. The Senate inquiry process

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<sup>&</sup>lt;sup>34</sup> Jones T. Intersex and Families: Supporting Family Members with Intersex Variations. Journal of Family Strengths. 2017;17(2).

<sup>&</sup>lt;sup>35</sup> ComLaw. Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013 [Internet]. Available from: <a href="http://www.comlaw.gov.au/Details/C2013A00098/">http://www.comlaw.gov.au/Details/C2013A00098/</a>

documented current medical practices and rationales,<sup>36</sup> understood to be reflected in a public submission to the inquiry by the Australasian Paediatric Endocrine Group (APEG). It stated that there are 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.<sup>37</sup>

Management of high cancer risks and urinary issues should not be controversial. However, documentation suggests that such issues are intertwined with non-therapeutic rationales for treatment.

A legal distinction between therapeutic and non-therapeutic treatment became part of Australian common law as a result of a 1992 judgment known as 'Marion's Case'. The ruling asserted a 'necessary' distinction between therapeutic and non-therapeutic treatment, despite lack of clarity about how the distinction is made. Therapeutic treatment, including incidental sterilisation, may broadly be considered to involve treatment of a malfunction or disease; this can be authorised by guardians as necessary, without court approval.<sup>38</sup>

However, a submission to the 2013 Senate inquiry by Cools and others shows how distinctions between therapeutic and non-therapeutic are arbitrary and can be intertwined, having lost any relationship to medical necessity for reasons of physical health. Specifically, a quotation from that private submission quoted in the Senate committee report shows how decision-making on sterilisation incorporates factors unrelated to physical health risks, and how this is assessed prior to a child's ability to freely express an identity:

In any individual with a DSD condition, the decision to perform gonadectomy is reached by weighing benefits and risks of various issues, such as risk for [germ cell tumour], sex of rearing, estimated capacity of the gonad to produce hormones in accordance with or opposite to sex of rearing and/or (developing) gender identity, likelihood of gender dysphoria later in life, etc.<sup>39</sup>

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<sup>&</sup>lt;sup>36</sup> Australian Senate, Community Affairs References Committee. Involuntary or coerced sterilisation of intersex people in Australia [Internet]. Canberra: Community Affairs References Committee; 2013 [cited 26 Oct 2013]. Available from:

http://www.aph.gov.au/Parliamentary Business/Committees/Senate/Community Affairs/Involuntary Sterilis ation/Sec Report/index

<sup>&</sup>lt;sup>37</sup> Australasian Paediatric Endocrine Group, Hewitt J, Warne G, Hofman P, Cotterill A. 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 [Internet]. Jun 2013 [cited 28 Jun 2013]. Available from:

http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191

<sup>&</sup>lt;sup>38</sup> Department of Health & Community Services v JWB & SMB ('Marion's Case') [1992] 175 CLR 218 at [48].

<sup>&</sup>lt;sup>39</sup> Cools M, Dessens A, Drop S, Hewitt J, and Warne G. Answers to questions on notice (received 27 Sep 2013). In Australian Senate, Community Affairs References Committee. Involuntary or coerced sterilisation of intersex people in Australia [Internet]. Canberra; 2013 [cited 26 Oct 2013]. Available from:

http://www.aph.gov.au/Parliamentary Business/Committees/Senate/Community Affairs/Involuntary Sterilis ation/Sec Report/index

In relation to cancer risks, actual risk levels are poorly understood in many cases; to a significant extent, this is due to the high prevalence of gonadectomies (sterilisations) in affected populations and a resulting inability, in high income countries, to establish control groups monitoring risk levels in intact individuals. A German multidisciplinary team advised Amnesty International this year 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'.<sup>40</sup>

The Senate Committee was 'disturbed' by the encapsulation of different rationales evidenced in clinical literature and submissions:

This kind of encapsulation of factors ... might happen because of the distinction made by Australian courts between 'therapeutic' and 'non-therapeutic' medical intervention. Treating cancer may be regarded as unambiguously therapeutic treatment, while normalising surgery may not. Thus basing a decision on cancer risk might avoid the need for court oversight in a way that a decision based on other factors might not. The committee is disturbed by the possible implications of this.<sup>36</sup>

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

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.<sup>37</sup>

We regard these as cultural, not functional, requirements for cosmetic interventions; and the stated psychosocial rationales lack evidence of necessity. APEG notes 'particular concern regarding sexual function and sensation' following these interventions.<sup>37</sup>

This issue has been raised in Australia over two decades, yet such interventions continue. For example, in 2004 Tony Briffa (a co-executive director of IHRA) wrote in a letter published in *Nature*:

the lasting effects of reducing potential for full enjoyment of sexual experiences are often ignored — along with a person's right to make informed decisions.<sup>41</sup>

No long-term follow-up takes place in Australia,<sup>37</sup> and handover from paediatric to adult services results in poor access to healthcare by adults, and a lack of clinical data on adult outcomes. Paediatric services are anyway poorly placed to determine long term outcomes, as they focus on only one single stage in the human lifecycle. Indeed, internationally, Creighton and others state that:

<sup>&</sup>lt;sup>40</sup> Amnesty International. First, Do No Harm. London: Amnesty International; 2017 May. Report No.: EUR 01/6086/2017.

<sup>&</sup>lt;sup>41</sup> Briffa T. Intersex surgery disregards children's human rights. Nature. 2004 Apr 15;428:695.

a schism has developed between clinicians working in paediatric and in adolescent/adult services. This has led to the defence of standard surgical practices by some paediatric clinicians against increasing interrogation of the practice by clinicians looking after adolescent and adult patients.<sup>42</sup>

In contrast, intersex peer support and advocacy organisations are fully cognisant of our health and human rights issues across the full human lifecycle.

In its 2013 report responding to submissions on involuntary or coerced sterilisation, the Senate 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.<sup>36</sup>

The core issue here is that medical professionals are defining interventions, including so-called 'normalising' interventions conducted for social and cultural reasons, as therapeutic. However, these rationales and procedures are contested, and lack both clinical consensus and evidence. There needs to be some form of oversight, but this is not happening effectively. Cases that require oversight are not receiving oversight. Cases that receive oversight from the Family Court are inadequately assessed.

### **6.2** Non-implementation of Senate report

The cross-party Senate report on involuntary or coerced sterilisation of intersex people called (on page 74) for protocols and guidelines consistent with recommendations by Intersex Human Rights Australia (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, particularly 4, 5 and 6.<sup>36</sup>

<sup>&</sup>lt;sup>42</sup> Creighton SM, Michala L, Mushtaq I, Yaron M. Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same? Psychology and Sexuality. 2014;5(1):34–43.

Those recommendations numbered 4, 5 and 6 are:

- 4. Medical interventions should not be based on psychosocial adjustment or genital appearance.
- 5. Medical intervention should be deferred wherever possible until the patient is able to freely give full and informed consent; this is known as "Gillick competence".
- 6. Necessary medical intervention on minors should preserve the potential for different life paths and identities until the patient is old enough to consent. (para 3.114)  $^{36}$

The Senate also provided guidance on implementing a human rights-affirming framework for such interventions:

3.97 The evidence suggests that a human rights consistent framework ... must necessarily operate from a presumption in favour of maintaining the [child's bodily] status quo for as long as possible except where such a presumption would conflict with the child's best interests. A model that confers rights on third parties, through substitute decision making, before it guarantees the rights of the child, is likely to be a disproportionate limitation of the child's right to autonomy/self-determination.<sup>36</sup>

In its 2015 response to the cross-party Senate inquiry, the federal government stated that 'the substantive regulation of medical treatment is a matter for state and territory governments'.<sup>43</sup> The government commended controversial and ineffective 2013 ethical guidelines produced in the State of Victoria that we discuss below.

No Australian government has implemented recommendations from the 2013 Senate committee report and, in May 2017, the report appears to have been finally rejected by the federal government.<sup>43</sup> No governmental attempts at redress have been made in Australia. The inclusion of 'intersex status' in anti-discrimination law appears not to have impacted upon harmful practices in institutional settings.

### 6.3 Flawed principles and derivative guidelines

A 2010 clinical ethical framework for the treatment of children with intersex variations was developed by Gillam, Hewitt and Warne at the Royal Children's Hospital, Melbourne, the University of Melbourne, and the Murdoch Children's Research Institute, Melbourne. <sup>44</sup> That framework states that psychosocial risks that can be minimised through medical intervention include:

<sup>&</sup>lt;sup>43</sup> Attorney General's Department. Australian Government response to the Senate Community Affairs References Committee reports on involuntary or coerced sterilisation. 2015 May.

<sup>&</sup>lt;sup>44</sup> Gillam LH, Hewitt JK, Warne GL. Ethical Principles for the Management of Infants with Disorders of Sex Development. Hormone Research in Paediatrics. 2010;74(6):412–8.

- Risk that child will not be accepted by parents in the chosen sex of rearing, leading to impaired bonding with associated negative consequences
- Risk of social or cultural disadvantage to child, for example, reduced opportunities for marriage or intimate relationships<sup>44</sup>

The inclusion of a risk related to impaired marriage prospects is, internationally, highly unusual, but it demonstrates the marked similarity between rationales favouring genital interventions on intersex children and rationales favouring Female Genital Mutilation in countries where that practice remains a norm. Given that marriage in Australia excluded same-sex couples until December 2017, such rationales are also heteronormative, promoting a heterosexual ideal on people born with intersex bodies.

The 2010 paper was criticised by some clinicians at the time, as focused on the continuing justification of surgical interventions, rather than alternative approaches that tackle stigma and shame. The paper was described as:

responding to the major DSD debate of a decade ago, namely over genital surgeries in infancy. Many have now recognized that the central challenge in DSD care is not centered on the surgeries per se, but rather finding a way to help families (and healthcare professionals) overcome the shame and anxious secrecy that may shape minds and force hands in ways that ultimately harm all involved.

#### Further:

The authors have opted to ignore the existing DSD ethics literature in an effort to arrive at principles putatively unburdened by previous ethical engagement.<sup>45</sup>

The methodology employed to develop the principles was described as reflective equilibrium. In this context, it appears that a small and homogeneous set of stakeholders (the three authors) established a set of principles without reference to external, dissenting or diverse viewpoints, and thus constructed a narrow position that is not defensible. Nevertheless, the authors have suggested that their ethical guidance was rolled out nationally.<sup>46</sup>

In 2013, a derivative ethical framework on the management of intersex infants, children and adolescents was published by the State of Victoria in 2013, with limited input from community organisations. This derivative ethical framework claims:

In the past, the birth of an infant born with an intersex condition was viewed as a medical and social 'emergency'. In some cases parents report not having been

<sup>&</sup>lt;sup>45</sup> Dreger A, Sandberg DE, Feder EK. From Principles to Process in Disorders of Sex Development Care. Hormone Research in Paediatrics. 2010;74(6):419–20.

<sup>&</sup>lt;sup>46</sup> Gillam LH, Hewitt JK, Warne GL. Ethical Principles: An Essential Part of the Process in Disorders of Sex Development Care. Hormone Research in Paediatrics. 2011;76(5):367–8.

given adequate information, time or options to provide informed consent or make informed decisions on behalf of their children.<sup>47</sup>

However, these issues persist today. In 2015, Victoria's Department of Health and Human Services published a Neonatal Handbook for clinicians that directly contradicted the Department's own 2013 ethical framework. It described the birth of an infant with ambiguous genitalia as:

rarely anticipated and can be a source of great distress for parents, delivery room and nursery staff.<sup>48</sup>

The situation should be treated as a medical emergency ...

Corrective surgery is usually undertaken within the first year of life but timing can be controversial. Very early surgery at under six months of age is less commonly performed than in the past<sup>48</sup>

This material was removed from the Department's website in April 2017,<sup>49</sup> in response to previous public disclosure of such material by IHRA (then OII Australia), including a submission to the Committee Against Torture in June 2016.<sup>50</sup> There is no evidence that the removal of this material from the Department's website has had any impact on clinical practices.

The Department currently (as at 1 May 2018) makes the following statements about children born with congenital adrenal hyperplasia:

Potential for cosmetic surgical correction of **ambiguous genitalia** for virilsed [sic] females should be discussed with the endocrinologist. Most surgical correction is now delayed until 6 months of age or later. Opinion currently varies between centres as to surgical management options.<sup>51</sup>

That is, it is up to multidisciplinary clinical teams to make their own judgements about indications and techniques for surgery. The Department's current (as at 1 May 2018) 'Better Health' page on congenital adrenal hyperplasia states:

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<sup>&</sup>lt;sup>47</sup> Victoria, Department of Health. Decision-making principles for the care of infants, children and adolescents with intersex conditions [Internet]. 50 Lonsdale Street, Melbourne: Victorian Government; Feb 2013 [cited 27 Feb 2013]. Available from: <a href="http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions">http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions</a>

<sup>&</sup>lt;sup>48</sup> Department of Health and Human Services. Ambiguous genitalia in neonates [Internet]. 2015 [cited 2017 Apr 2]. Available from: <a href="https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/congenital-abnormalities/ambiguous-genitalia">https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/congenital-abnormalities/ambiguous-genitalia</a>

<sup>&</sup>lt;sup>49</sup> OII Australia. Gaslighting in Victoria [Internet]. 2017 May 18 [cited 2017 May 18]. Available from <a href="https://oii.org.au/31391/gaslighting-in-victoria/">https://oii.org.au/31391/gaslighting-in-victoria/</a>

<sup>&</sup>lt;sup>50</sup> Carpenter M, Organisation Intersex International Australia. Contribution to the List of Issues Prior to Reporting to the Committee against Torture for Australia [Internet]. Sydney; 2016 Jun [cited 2016 Jun 29]. Available from: <a href="https://oii.org.au/30546/loi-cat-review/">https://oii.org.au/30546/loi-cat-review/</a>

<sup>&</sup>lt;sup>51</sup> Department of Health & Human Services. Congenital adrenal hyperplasia (CAH) in neonates [Internet]. [cited 2017 Jun 8]. Available from: <a href="https://www2.health.vic.gov.au:443/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/conditions/congenital-adrenal-hyperplasia">https://www2.health.vic.gov.au:443/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-ehandbook/conditions/congenital-adrenal-hyperplasia</a>

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

The clitoral reduction or recession is done is the first few months of life. The vaginoplasty is sometimes done at the same time as the clitoral reduction, but may be left until adolescence, before the menstrual periods begin.<sup>52</sup>

This description matches the description for 'vulvoplasties' in Medicare and AIHW data.

The 2013 Victorian guidelines have demonstrably not been binding on either the State or its hospitals, and have been disregarded in subsequent Departmental policy. Nevertheless, the guidelines were commended in the government's response to the Senate Community Affairs References Committee reports on involuntary or coerced sterilisation (see, for example, page 19). <sup>43</sup> IHRA does not support the guidelines as they do not provide human rights-based standards of care.

Queensland has also published an endorsement of current practices, including conceptions of 'normality' and 'gender affirmation'; that is, language borrowed from the treatment of trans persons exercising their capacity to affirm their internal identity, but in children who may not be in a position to affirm or contribute to decision-making. The 2016 Queensland Sexual Health Strategy illustrates a deeper problem:

Informed consent from legal guardians is also essential if treatment is to be undertaken on children and young people later in life for normalisation and gender affirmation...

Medical treatment is sometimes necessary to help development proceed as normally as possible and for some conditions, surgical treatment may be recommended<sup>53</sup>

However, as the 2013 Senate cross-party report noted:

3.98 One of the difficulties that is seldom discussed is how to establish what constitutes 'normal', particularly in relation to what genitals 'should' look like. OII expressed concern about 'the absence of standard objective measures for cosmetic perceptions of "normal" female genitals'.126 The Androgen Insensitivity Syndrome Support Group Australia held a similar view of current medical practice...

<sup>&</sup>lt;sup>52</sup> Department of Health & Human Services. Congenital adrenal hyperplasia (CAH) [Internet]. 2014 [cited 2016 Jun 8]. Available from: <a href="https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/congenital-adrenal-hyperplasia-cah">https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/congenital-adrenal-hyperplasia-cah</a>

<sup>&</sup>lt;sup>53</sup> Queensland Health. Queensland Sexual Health Strategy [Internet]. 2016 Dec [cited 2017 Jul 4]. Report No.: QH845 11/16. Available from: <a href="https://www.health.qld.gov.au/public-health/topics/sexual-health/strategy">https://www.health.qld.gov.au/public-health/topics/sexual-health/strategy</a>

3.100 What little research exists regarding 'adequate' or 'normal' genitals, particularly for women, raises some disturbing questions ... The committee received no information indicating whether or not this natural variation in genital size and shape is taken account of in areas such as the application of the Prader scale, or how medical specialists learn about the diversity of appearance of genitals or how they define 'normal' in their clinical practice.

In the few cases where it has provided oversight, the Family Court has been unable to respond to such issues.

### 6.4 Data on human rights violations in medical settings

Little statistical information is available on historic and current medical practices, though we are given to understand from discussions with clinicians that individual multidisciplinary teams know very little about the actual practices of other teams, and a high degree of variability in practices was reported to the Senate in 2013. Factors driving this variability may include, multidisciplinary team leadership, and clinician specialism, age and gender, personal dispositions and beliefs about concepts of normality, sex and gender. Factors driving the sex and gender.

Limited information becomes periodically available from hospitals in press reports and peer-reviewed journals, indicating that information is stored, albeit carefully curated. For example, the Royal Children's Hospital Melbourne reported to the media in 2013 that it performs 10-15 'genital reconstruction operations a year often on girls under the age of two' each year. 55 Variability between hospitals and their lack of transparency negate broad or unsubstantiated claims of change to clinical practices and surgery numbers.

Some national data on surgical procedures by the Australian Institute of Health and Welfare is currently available for some periods. The data available for the year 2013-2014 showed a national total of 6 'procedures for anomalies of genitalia' in female-assigned age groups 0-19 years. However, this is contradicted (and exceeded) in a contemporaneous disclosure by a single hospital to the media (the Royal Children's Hospital Melbourne, as mentioned above) suggesting that data are displaced to other, potentially less contentious, procedure codes. In a submission to the religious freedoms inquiry, Morgan Carpenter reports:

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<sup>&</sup>lt;sup>54</sup> See, for example, note 28 and Reitsma W, Mourits MJE, Koning M, Pascal A, van der Lei B. No (Wo)Man Is an Island-The Influence of Physicians' Personal Predisposition to Labia Minora Appearance on Their Clinical Decision Making: A Cross-Sectional Survey: Labia Minora Reductions: Physicians' View. The Journal of Sexual Medicine. 2011 Aug;8(8):2377–85.

<sup>&</sup>lt;sup>55</sup> Bock A. It takes more than two. The Age. 2013 Jun 20; Available from: http://www.theage.com.au/national/it-takes-more-than-two-20130619-20j8v.html

<sup>&</sup>lt;sup>56</sup> This information is extracted from: Carpenter M. The 'normalisation' of intersex bodies and 'othering' of intersex identities, the experience in Australia. In: Scherpe J, Dutta A, Helms T, editors. The Legal Status of Intersex Persons. 1st ed. Cambridge, England: Intersentia; 2018 (forthcoming).

<sup>&</sup>lt;sup>57</sup> Australian Institute of Health and Welfare. Procedures data cubes [Internet]. 2017 [cited 2017 Feb 27]. Available from <a href="http://www.aihw.gov.au/hospitals-data/procedures-data-cubes/">http://www.aihw.gov.au/hospitals-data/procedures-data-cubes/</a>

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

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

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

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

### 6.5 Female genital mutilation

Female Genital Mutilation 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'.<sup>62</sup> International health and human rights institutions state that the practice continues in many parts of the world, due to gender inequality, traditional and normative gender roles, including perceptions that the ritual facilitates women's fuller participation in society, and that the procedure prepares women for adulthood.<sup>62</sup>

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<sup>&</sup>lt;sup>58</sup> Defined in the Review as 'any surgery performed on the outside female genital structures' thereby including labioplasties and clitorectomies

<sup>&</sup>lt;sup>59</sup> Department of Health. MBS Reviews Vulvoplasty Report [Internet]. Department of Health; 2014 Apr [cited 2017 Sep 30]. Available from:

http://www.health.gov.au/internet/main/publishing.nsf/content/E393B5FFC5978400CA257EB9001EEC59/\$File/Vulvoplasty Review Report.pdf

<sup>&</sup>lt;sup>60</sup> Australian Institute of Health and Welfare. Procedures data cubes. 2002-2017 [Internet]. 2017 [cited 2017 Sep 30]. Available from: <a href="http://www.aihw.gov.au/hospitals-data/procedures-data-cubes/">http://www.aihw.gov.au/hospitals-data/procedures-data-cubes/</a>

<sup>&</sup>lt;sup>61</sup> Carpenter M. The 'normalisation' of intersex bodies and 'othering' of intersex identities, the experience in Australia. In: Scherpe J, Dutta A, Helms T, editors. The Legal Status of Intersex Persons. 1st ed. Cambridge, England: Intersentia; 2018 (forthcoming).

<sup>&</sup>lt;sup>62</sup> World Health Organization, Office of the High Commissioner for Human Rights, UNAIDS, UNDP, UNECA, UNESCO, et al. Eliminating female genital mutilation: an interagency statement. Geneva: World Health Organization; 2008.

UN institutions recognise that, in some cases, parents may be motivated to consent to female genital motivation because they see other parents doing so, while women subjected to the procedure may also exert pressures that promote conformity and ostracize others. Personal consent is not recognised as a justification for FGM. The World Health Organization and other bodies recognize that medicalization, including as a form of harm reduction, does not justify FGM. Personal consent is not recognize that medicalization, including as a form of harm reduction, does not justify FGM.

Despite this prohibition of FGM, labioplasties and other vulvoplasties, including for aesthetic purposes, are permitted.<sup>64</sup> The Department of Health has investigated a 'marked increase' of 105% in numbers of Medicare-funded vulvoplasties and labioplasties in adolescents and adults between 2003/4 and 2012/13.<sup>59</sup>

Aesthetic rationales for surgery appear in promotional literature on labioplasties produced by Australian plastic surgeons. It is not clear on what basis such practices can be supported when conducted for cosmetic or aesthetic reasons, other than by the informed consent of the recipient.

Exemptions in the Model Criminal Code do not apply to cosmetic interventions. However, exemptions in Australian Jurisdictions dealing with female genital mutilation reflects profound confusion about intersex, as they appear to describe intersex infants as 'neither female or male', regardless of their actual sex assignment, until they receive surgical reinforcement of those sex assignments. The Model Code permits genital surgeries on intersex people as 'sexual reassignment procedures' that 'give a female, or a person whose sex is ambivalent,[sic] the genital appearance of a particular sex'. <sup>65</sup> This policy framework does not discuss issues of necessity or evidence in support of medical interventions, perhaps assuming that medical interventions will be supported by both. However, neither are the case for infants and children with intersex variations. Actual rationales, including parental distress and cosmetic issues (such as appearance enhancement, marriageability) mirror the rationales evident for FGM in societies where FGM is the norm.

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<sup>&</sup>lt;sup>63</sup> Committee on the Elimination of Discrimination against Women, General Comment 31, and Committee on the Rights of the Child, General Comment 18 (CEDAW/C/GC/31-CRC/C/GC/18), 2014, para 57

<sup>&</sup>lt;sup>64</sup> Kennedy A. Mutilation and Beautification. Australian Feminist Studies. 2009 Jun 1;24(60):211–31. Spriggs M. Parent-led request for female genital cosmetic surgery in an adolescent. In: McDougall R, Delany C, Gillam L, editors. When Doctors and Parents Disagree: Ethics, Paediatrics and the Zone of Parental Discretion. Annandale, NSW: Federation Press; 2016. p. 227–43.

Spriggs M, Gillam L. Body Dysmorphic Disorder: Contraindication or Ethical Justification for Female Genital Cosmetic Surgery in Adolescents: Body Dysmorphic Disorder. Bioethics. 2016;30(9):706–13. Shahvisi A, Earp BD. The Law and Ethics of Female Genital Cutting. In: Creighton S, Liao L-M, editors. Female Genital Cosmetic Surgery: Interdisciplinary Analysis & Solution. Cambridge, England: Cambridge University Press; 2018.

<sup>&</sup>lt;sup>65</sup> Attorney General's Department. Review of Australia's Female Genital Mutilation legal framework - Final Report [Internet]. 2013 May [cited 2013 May 25]. Available from:

 $<sup>\</sup>underline{http://www.ag.gov.au/Publications/Pages/ReviewofAustraliasFemaleGenitalMutilationlegalframework-} \\ \underline{FinalReportPublicationandforms.aspx}$ 

#### 6.6 Sex classifications and interactions with medicine

### 6.6.1 Federal guidelines

The *Darlington Statement* demands on sex markers arise because Australian governments, and other institutions, have constructed intersex is a third sex, or a gender identity, and this same presumption is evident in paragraph 90 of the ALRC Issue Paper. However, constructing intersex as a third sex or gender category causes harm because it regards intersex women as not women, and intersex men as not men, including where intersex women and men identify with sex assigned at birth. In part, federal sex and gender recognition guidelines are under review because of this. Currently they state that:

Intersex people have a diversity of bodies and gender identities, and may identify as male or female or neither (para 12)<sup>66</sup>

This is as a non-exhaustive list but describes the limited options available within the guidelines. Contradictorily, the guidelines state that:

individuals should be given the option to select M (male), F (female) or X (Indeterminate/Intersex/Unspecified). (para 19)

#### And also:

If the X descriptor set out at paragraph 19 is too lengthy for collection forms or data systems, the Australian Government's preference is to use either 'unspecified' or 'indeterminate'. This classification system is consistent with the Australian Government passports policy for applicants who are sex and gender diverse and Australian Standard AS4590 – Interchange of client information. (para 21)

IHRA hopes that contradictions written into the guidelines will be resolved in the following ways.

The Attorney General's Department has advised us that, in 2017, the Australian Standard AS4590 – Interchange of client information was updated such that the following changes have been made:

- 3.5.6 Gender Code change in definition of code 3 from 'indeterminate' to 'Non-Binary' (page 26).
- 3.5.5 Sex Code change in definition of code 3 from 'intersex or indeterminate' to 'indeterminate' (page 25).<sup>67</sup>

<sup>&</sup>lt;sup>66</sup> Attorney General's Department, Australia. Australian Government Guidelines on the Recognition of Sex and Gender. 2015 [cited 2015 Nov 18]. Available from:

 $<sup>\</sup>underline{\text{http://www.ag.gov.au/Publications/Pages/AustralianGovernmentGuidelinesontheRecognitionofSexandGender}. aspx$ 

<sup>&</sup>lt;sup>67</sup> Wallace L (Attorney General's Department). Update - Sex and Gender Recognition Guidelines [SEC=UNCLASSIFIED]. 2017.

These changes are in line with a 2015 joint letter to the Attorney General's Department by the National LGBTI Health Alliance, A Gender Agenda, Organisation Intersex International Australia, Trans Formative, Transgender Victoria, requesting that the definition of 'X' be changed to non-binary.<sup>68</sup>

IHRA continues to oppose use of the term intersex to signify a sex classification in line with paragraph 4 of the *Darlington* Statement and because of its collateral impact on intersex people with other sex classifications and binary gender identities; that is, a legal classification called intersex constrains their ability to self-determine sex and gender. We understand that governments and other institutions may need to collect statistical information on sex or gender. The Darlington Statement does not prevent this, it facilitates data collection on the basis of personal choice, which is typically the basis on which individuals make decisions when completing forms and documents. The Statement simply argues that governments should move to a situation where they do not classify individuals by sex or gender.

### 6.6.2 State and Territory laws and regulations

In 2014, the government of the Australian Capital Territory adopted a policy framework establishing new sex categories, including 'intersex', and with those classifications available for infants and children, at the same time that the same government defended its medical treatment of infants and children with 'DSDs' in correspondence with OII Australia.

The Hon. Katy Gallagher, then the ACT Chief and Health Minister, wrote in April 2014 that the creation of a new sex category would address issues around coercive medical interventions on infants and children:

The availability of the third marker for children will also reduce the risk that parents will force their child to conform to a particular gender or subject them to gender assignment surgery or other medical procedure to match the child's physical characteristics to the chosen sex<sup>69</sup>

However, a clinical framing of intersex variations as 'disorders of sex development' is evident in a contradictory but contemporaneous letter from the same Minister, a couple of months prior:

Currently in the ACT, in the event of a birth of a baby with a disorder of sex development (DSD), clinicians follow a standard investigation and management practice that is consistent with a national approach from the Australasian Paediatric Endocrine Group and international consensus statements from key

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<sup>&</sup>lt;sup>68</sup> National LGBTI Health Alliance, A Gender Agenda, Organisation Intersex International Australia, Trans Formative, Transgender Victoria. RE: Commonwealth Attorney-General's Department Review of the Australian Government Guidelines on the Recognition of Sex and Gender. 2015 [cited 2015 Oct 12]. Available from: <a href="http://lgbtihealth.org.au/resources/submission-review-agd-guidelines/">http://lgbtihealth.org.au/resources/submission-review-agd-guidelines/</a>

<sup>&</sup>lt;sup>69</sup> Communication by Katy Gallagher, writing as Chief and Health Minister of ACT, to Morgan Carpenter, then president of OII Australia, 15 April 2014.

disciplines such as paediatric endocrinology, surgery... it is recognised that surgery of this sort is best performed in centres of excellence. For this reason children with a DSD are normally referred to either Melbourne or Sydney.<sup>70</sup>

When we review the two letters from the Minister, we observe contradictory statements, including statements that 'standard' practices in state-funded hospitals are 'risks', claims of clinical consensus, and a description of national norms. The letters describe two fundamentally different, both un-evidenced, approaches to the same population. As described by Morgan Carpenter:

The government was not able to create a well-formed policy because it does not possess a coherent understanding of the population affected $^{71}$ 

Effectively, the ACT government treated persons with 'DSDs' as if they are a separate population to persons with intersex traits.

The current data available to us have shown that no parents in the ACT have used a new sex classification to assign an infant. Indeed, our view is that such novel assignments reinforce and exacerbate surgical interventions due to a parental desire for perceived certainty, and the avoidance of disclosure and stigma.

In an approach similar to that of the Australian Capital Territory, and without adequate consultation, the government of South Australia introduced similar new birth registration categories in 2017, adding that it has acted to:

remove the requirement that the sex of the child be recorded on the Birth Register where the sex of a child is indeterminate<sup>72</sup>

This was previously unannounced and it was not sought by intersex-led organisations. As with the ACT policy framework, it singles out intersex infants for different treatment and a separate legal status, resulting in concerns about disclosure and exposure to discrimination.

It is not clear what kind of relationship, if any, the new regulation has with existing actual processes, policies and procedures in hospitals in South Australia. Clinicians in South Australia participate in APEG, with the same general clinical principles applying across Australia and New Zealand.

The situation in ACT and South Australia reflect a situation described by Morgan Carpenter as one where:

<sup>&</sup>lt;sup>70</sup> Communication by Katy Gallagher, writing as Chief and Health Minister of ACT, to Morgan Carpenter, then president of OII Australia, 21 January 2014.

<sup>&</sup>lt;sup>71</sup> Carpenter M. The human rights of intersex people: addressing harmful practices and rhetoric of change. Reproductive Health Matters [Internet]. 2016 May [cited 2016 Jul 13];24(47):74–84.

<sup>&</sup>lt;sup>72</sup> Communication by the Hon. Jay Weatherill, Premier of South Australia, and colleagues, to Morgan Carpenter, co-executive director of OII Australia, 18 May 2017.

Claims that medicalization save intersex people from "othering", or that legal othering saves intersex people from medicalization, are contradictory and empty rhetoric. In practice, intersex bodies remain "normalized" or eliminated by medicine, while society and the law "others" intersex identities. That is, medicine constructs intersex bodies as either female or male, while law and society construct intersex identities as neither female nor male. [Thus] Australian attempts at reforms to recognize the rights of intersex people have either failed to adequately comprehend the population affected or lacked implementation.<sup>73</sup>

This situation harms our population.

### 7 Family Court cases on the treatment of intersex children

Few cases on the treatment of intersex children are put to the Family Court for consideration. Such cases have typically involved sterilisation (irrespective of fertility) or been incidental to treatment for gender dysphoria in an intersex child. in each situation, the individuals consequently require a lifetime of hormone replacement. It is notable that relevant Family Court cases rarely employ the term intersex, nor the current clinical term 'disorders of sex development'; they most frequently refer to a specific intersex variation using a diagnostic term.

A subset of recent and recently cited cases are discussed in this section. They include cases before the federal Family Court in both 2016 and 2017 that demonstrate what Melinda Jones describes as 'the culpability of health systems and the medical profession' and a 'failure of the state to protect the rights' of children with intersex variations. A third 1993 case cited by the Chief Justice of the Family Court in her submission to the 2013 Senate inquiry is also discussed. The cases give rise to serious concerns about equality before the courts and tribunals (ICCPR article 14), including access to justice, undue restrictions on legal capacity, and legal and governmental complicity in harmful, current clinical practices.

### 7.1 *Welfare of a Child A* (1993)

In 2013, the Hon. Diana Bryant AO made a submission to the Senate inquiry on involuntary or coerced sterilisation. In her submission, the former Chief Justice cited the case of *Welfare of a Child A* [1993] FamCA 68.<sup>76</sup> The adolescent boy in this case was diagnosed with congenital adrenal hyperplasia (CAH) at birth (at [5]), and presented as suicidal.

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<sup>&</sup>lt;sup>73</sup> Carpenter M. The 'Normalization' of Intersex Bodies and 'Othering' of Intersex Identities in Australia. Journal of Bioethical Inquiry. 2018;15(4).

<sup>&</sup>lt;sup>74</sup> Jones M. Children's Health Rights and Gender Issues. In: Children's Rights in Health Care. Leiden: Brill; (forthcoming).

<sup>&</sup>lt;sup>75</sup> The Hon. Diana Bryant, AO, Chief Justice. Submission to the Senate Community Affairs Committee Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia. 2013 Feb 22. Available from: <a href="http://www.aph.gov.au/DocumentStore.ashx?id=75906320-b2bb-43dd-9d0a-3fe58a7d93f9&subId=16140">http://www.aph.gov.au/DocumentStore.ashx?id=75906320-b2bb-43dd-9d0a-3fe58a7d93f9&subId=16140</a>

<sup>&</sup>lt;sup>76</sup> Welfare of a Child A [1993] FamCA 68; (1993) FLC 92-402 16 Fam Lr 715 Children (30 June 1993).

Legally registered male with a male birth certificate (at [7]), the child was described clinically as a 'genetic female' due to XX sex chromosomes, and subjected to early 'feminising' surgeries (at [10]).

Furtado and others have stated in a 2012 clinical review that generally 'between 8.5–20% of individuals with DSDs' will experience distress associated with their gender assignment, including one in ten individuals with CAH. They state nonetheless that: 'Early surgery seems to be a safe option for most' children with that diagnosis. Feen discounting known consequences for sexual function and sensation (not mentioned in this clinical review), there is no method of distinguishing those whose gender identity will change from those whose identity will not. Such surgeries remain the standard protocol for children with CAH.

Justice Mushin, now an adjunct professor of law at Monash University, Victoria, did not question these 'feminising' surgeries in his judgment but was, instead, critical of the parents, blaming the mother for the child's male gender identity. He stated:

- 9. The application which is made by the mother seeks authorisation from the court that A be permitted to undergo bilateral mastectomies, a hysterectomy and oophorectomy...
- 10. The background for this is well expressed by the surgeon. His report, to the extent that it is relevant, is in the following terms:

  Following investigation after birth, this child was correctly assessed as being a genetic female with an extreme degree of masculinization. The degree of masculinization is variable and depends on the severity of the original abnormality in the adrenal gland. In some children this is mild and in others it is severe. However, in all cases it would be standard medical practise (sic) to raise the child as a female with a potential for normal female fertility. The genitalia are therefore operated on in the postnatal period to make them feminine in appearance. This advise (sic) and treatment was carried out in (A's) early years and she had genital reconstruction to give her a feminine appearance. She was also given cortisone hormone treatment to replace the absent hormone and prevent any further masculine hormones being produced by the abnormal adrenal gland...
- 12. Further in that report the endocrinologist states:
  As (A's) endocrinologist, I consider her to be completely male in her outlook due to the prenatal and postnatal exposure to excessive levels of adrenal androgen. I do not believe that this situation is reversible...
- 13. I am critical of both the parents, and particularly the mother, that the treatment recommended by the doctors at the time of the A's birth was not pursued. It appears on the basis of the material which is available to me that had that treatment been undertaken it may well have been possible to avoid the

<sup>&</sup>lt;sup>77</sup> Furtado PS, Moraes F, Lago R, Barros LO, Toralles MB, Barroso U. Gender dysphoria associated with disorders of sex development. Nature Reviews Urology. 2012;9:620–7.

appalling situation which has now arisen and in respect of which I am asked to make this decision.

We note that the difficult situation presented in the judgment would not have been appalling at all, had the boy not been subjected to unnecessary early surgeries, yet the judge did not comment at all on their necessity or the appalling consequences for this child. All subsequent surgeries were in line with the child's legal sex, original sex assignment and gender identity, and were sought to support his male sex of living.

In most scenarios, the early 'feminising' surgeries on children with XX sex chromosomes (a 'genetic female') would be described as female genital mutilation. If child A was to be regarded as a girl, as clinicians did, then policies prohibiting female genital mutilation should have applied. However, we note a specific exemption in Australian policy frameworks that (perhaps inadvertently) permit medical interventions despite lack of evidence of necessity.

The judge was egregious in criticism of the parents. As identified by the Committee on Bioethics of the Council of Europe, there is no evidentiary basis to claim that medical interventions or parents can influence gender development.<sup>30</sup>

In her comments on the case in 2013, the Chief Justice of the Family Court stated that 'the trial judge found that A had "an overwhelming expectation and desire to have the operations referred to so that he may assume what he regards as being his right and expectation, that is to become a male in all possible respects".'75 That is, the Chief Justice of the Family Court also chose not to comment on the appropriateness, indications, necessity or evidence for earlier 'feminising' surgeries.

### 7.2 Re: Carla (Medical procedure) (2016)

The case of *Re: Carla (Medical procedure)* [2016] FamCA 7 was initiated by the parents of a child pseudonymously named Carla. An anonymous State government department was appointed as a friend of the court.<sup>78</sup>

Carla was 'born in 2010, is now five years of age and is about to start school', and 'was born with a sexual development disorder, described, in more particular medical terms, as 17 beta hydroxysteroid dehydrogenase 3 deficiency' (at [1]), with XY sex chromosomes, testes, and predominantly female genitalia.

Justice Forrest stated that 'the proposed surgery for Carla involving the bilateral removal of her gonads ("gonadectomy") ... may be authorised by either of Carla's parents'. This has taken similar cases out of Court jurisdiction.

Justice Forrest argued that the gonadectomy (sterilisation) was justifiable on the basis of a potential cancer risk, stating that 'the Consensus Statement for Management of Disorders of Sexual Development puts the risk of germ cell malignancy at 28% ... said to be an intermediate level of risk of malignancy' (at [19]) and it was '...virtually impossible to

<sup>&</sup>lt;sup>78</sup> Re: Carla (Medical procedure) [2016] FamCA 7 (20 January 2016)

regularly monitor them for the presence of tumours' (at [20]). There is no evidence for this. As previously mentioned, a German multidisciplinary team advised Amnesty International this year that, cancer risk can be monitored effectively even for high risk groups.<sup>40</sup>

Indeed, the medical journal article referenced in the judgment was consciously misquoted, seemingly to avoid mentioning the word intersex, and the actual 'Consensus statement on management of intersex disorders', citing a risk of 28%, itself states that clinicians should 'monitor' gonads in children with 17 beta hydroxysteroid dehydrogenase 3 deficiency (17ßHSD). In other words, the current international position recommends against surgery in favour of a more cautious monitoring. A more recent clinical review published in 2010 reduces estimates of risk levels to 17%. According to clinical literature, the retention and monitoring of gonads should have been unambiguously supported. This is in line with best practice, as evidenced by the German team that advised Amnesty International. The medical evidence cited in the judgment identifies cancer risk as the therapeutic justification for sterilisation, although a gonadectomy in those circumstances is not consistent with established best practice even within a conservative medicalised paradigm.

Given the length and detail of the supporting information, it appears that gender stereotyping substantively comprises the rationale for sterilisation, mostly on the basis of parental reporting and clinical affidavits:

- 15. In 2014, when Carla was almost four years of age, she was reviewed by Dr S who formed the opinion that Carla had developed a female gender identity and identified as a female and that this was unlikely to change in the future. Dr S formed this opinion based on the following observations:
  - 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. (at [15])

The reliance on such crude gender stereotyping illustrates clearly our concerns with current medical practices, and is disturbing. Furthermore, these were third party report; the Court is

<sup>&</sup>lt;sup>79</sup> Hughes IA, Houk C, Ahmed SF, Lee PA, LWPES/ESPE Consensus Group. Consensus statement on management of intersex disorders. Archives of Disease in Childhood. 2006;91:554–63.

<sup>&</sup>lt;sup>80</sup> Pleskacova J, Hersmus R, Oosterhuis JW, Setyawati BA, Faradz SM, Cools M, et al. Tumor Risk in Disorders of Sex Development. Sexual Development. 2010;4(4–5):259–69.

not required to give a child an opportunity to express their own views.<sup>81</sup> Carla is not yet an independent agent and presumably the gender performance described in the above extract reflects the parents' choices and actions rather than (or at least as much as) the preferences of Carla herself. Given the absence of clear medical evidence in support of Carla's sterilisation, her current gender presentation and future gender identity are irrelevant. Similarly, no-one can be confident of her future gender identity and sexual orientation; these are simply unknown. However, we note that Australian clinical literature, published in 2009, states:

As is well known, spontaneous change of gender identity from female to male occurs after the onset of puberty in 46,XY children with ... 176-hydroxysteroid dehydrogenase deficiency.<sup>82</sup>

The medical literature on this issue is clear: many children with Carla's diagnosis undergo spontaneous change of gender identity at puberty. The conclusion of the psychiatric expert expressing confidence that Carla's gender identity was stable at age 3/almost 4 (at[15]) is directly at odds with the 'well known' experience evidenced in the clinical literature.

Further, Justice Forrest suggested that sterilisation should deliberately proceed early, prior to the child's ability to consent, stating that it would be:

less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure (at [30])

This action appears to infringe articles 14 and 24 of the ICCPR,<sup>83</sup> guaranteeing equality before the law and protection without discrimination, and article 12 of the Convention on the Rights of Persons with Disabilities guaranteeing equal recognition before the law and the exercise of legal capacity.<sup>84</sup> Despite this justification for early sterilisation, we note that Justice Forrest made no such claim about trauma arising from a different possible medical intervention:

Carla may also require other surgery in the future to enable her vaginal cavity to have adequate capacity for sexual intercourse. (at [18])

This focus on the suitability of Carla's body for heterosexual intercourse reflects heteronormative assumptions and values; and approach validated in a Victorian 2010 ethical framework that enumerated marriage prospects amongst rationales for medical intervention.

<sup>&</sup>lt;sup>81</sup> Commonwealth of Australia. Family Law Act 1975 - Sect 60CD How the views of a child are expressed [Internet]. Available from: <a href="http://www8.austlii.edu.au/cgi-bin/viewdoc/au/legis/cth/consol">http://www8.austlii.edu.au/cgi-bin/viewdoc/au/legis/cth/consol</a> act/fla1975114/s60cd.html

<sup>82</sup> Hewitt JK, Warne GL. Management of disorders of sex development. Pediatric Health. 2009;3(1):51–65.

<sup>&</sup>lt;sup>83</sup> Office of the High Commissioner for Human Rights. International Covenant on Civil and Political Rights. 1966.

<sup>&</sup>lt;sup>84</sup> United Nations. Convention on the Rights of Persons with Disabilities [Internet]. Geneva: United Nations; [cited 2015 Mar 23]. Available from: <a href="http://www.un.org/disabilities/convention/conventionfull.shtml">http://www.un.org/disabilities/convention/conventionfull.shtml</a>

Despite rhetoric to the effect that the medical team and the parents had patiently deferred any irrevocable intervention until Carla was developmentally able to express a fixed gender identity, the fact that feminising genital surgeries had already been performed well before the hearing indicates that the parents and medical team were not content to wait until Carla had formed a fixed gender identity before commencing interventions that explicitly and irreversibly shaped her body towards a 'feminine' appearance. The applicants and the expert witnesses had become irrevocably invested in Carla being assigned and physically shaped as a female before these proceedings had commenced.

Finally, Carla's medical history was also put before the Family Court:

Surgery already performed on Carla has enhanced the appearance of her female genitalia. (at [2])

In 2014, Carla underwent ... a 'clitoral' recession and labioplasty (at [16])

These abhorrent, irreversible, non-therapeutic and invasive interventions were disclosed as incidental to a case brought to sterilise the child. This raises concern about a conflict of interest, where both clinicians and parents are invested in the success of early surgical interventions.<sup>85</sup>

A clitoral recession and labioplasty fit the criteria for 'vulvoplasties'. As described above, we note that the 2014 Department of Health Medicare Benefits Schedule Review on 'vulvoplasties' identified 371 Medicare-funded vulvoplasties for so-called 'congenital malformations' during the period 2007/8 to 2011/2; an average of 74.2 per year; and a similar number of 'vulvoplasties' are performed on children aged under 15. Australia, in common with many other countries, maintains a legal prohibition on Female Genital Mutilation including all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for 'non-medical reasons'. Cultural standards relating to genital appearance are not recognised as valid medical reasons for FGM. Further, the World Health Organization and other bodies recognize that medicalization, including as a form of harm reduction, does not justify FGM.

The Australasian Paediatric Endocrine Group recommends such interventions to address psychosocial rationales despite 'particular concern' about post-surgical 'sexual function and sensation', <sup>37</sup> and evidence favouring those interventions has been criticised by intersex-led organisations and many other institutions, including the Australian Senate<sup>36</sup> and the Committee on Bioethics of the Council of Europe.<sup>30</sup> Nevertheless, it is evident that such harmful practices take place within medical settings without any requirement for independent oversight, whether from the Family Court or other avenues.

Unnecessary medical interventions such as genital appearance 'enhancing' interventions, should not be regarded as therapeutic.

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<sup>&</sup>lt;sup>85</sup> An early case note can be found at: Carpenter M. The Family Court case Re: Carla (Medical procedure) [2016] FamCA 7 [Internet]. Intersex Human Rights Australia. 2016 [cited 2016 Dec 7]. Available from: <a href="https://ihra.org.au/31036/re-carla-family-court/">https://ihra.org.au/31036/re-carla-family-court/</a>

The child's sterilisation should not have been approved on the basis of the evidence and reasoning presented in the judgment. Further, the decision to enable parental choice on sterilisation has taken future sterilisation cases out of Court jurisdiction, for the 'potential benefit of any parents, like them, who might find themselves in these very same factual circumstances in the future' (at [8]). The far-reaching consequences of this decision are alarming given the evidence of human rights breaches.

It is not clear that either Carla's parents or the Court were provided with accurate and comprehensive information or medical evidence supporting the interventions on the child. It appears that the family have had no access to independent peer support.

Overall, this 2016 Family Court of Australia case is deeply disturbing, exemplifying the way that the human rights of intersex children are violated with inadequate evidence for social and cosmetic purposes.

IHRA board members and many other individuals have personally experienced similar interventions, with negative personal and familial consequences. <sup>86</sup> There are multiple publicly available documents attesting to the experiences of intersex people who have been subjected to unnecessary medical interventions such as these. It is a telling criticism that Justice Forrest seems oblivious to the strong and diverse challenges to the medicalised approach adopted by the team of experts responsible for Carla's care, despite the comprehensive outline of these challenges in the Report of the Senate Committee published in 2013.

### 7.3 Re: Lesley (Special Medical Procedure) (2008)

In the Family Court case *Re Lesley (Special Medical Procedure)* [2008] FamCA 1226, a judge approved the sterilisation of a young child with the same intersex variation as the child in *Re: Carla* (i.e. 17ß-HSD3).<sup>87</sup> The facts of this case are substantively the same as those in *Re: Carla*, albeit that clinical rationales and any genital surgeries were not disclosed in the same manner, and the Court did not take subsequent approval processes out of Court jurisdiction. Risks of gonadal tumour were stated to be 'significant' (at [40]). While a later re-evaluation of risks had not yet been published,<sup>80</sup> clinical guidance recommending the monitoring of gonads had been published.<sup>79</sup> There was no clinical consensus supporting removal of gonads.

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<sup>&</sup>lt;sup>86</sup> Copland S. The medical community's approach to intersex people is still primarily focused on "normalising" surgeries [Internet]. SBS. 2016 [cited 2016 Dec 15]. Available from:

 $<sup>\</sup>frac{http://www.sbs.com.au/topics/sexuality/agenda/article/2016/12/15/medical-communitys-approach-intersex-people-still-primarily-focused-normalising}{\frac{http://www.sbs.com.au/topics/sexuality/agenda/article/2016/12/15/medical-communitys-approach-intersex-people-still-primarily-focused-normalising}$ 

Overington C. Family Court backs parents on removal of gonads from intersex child. The Australian [Internet]. 2016 Dec 7 [cited 2016 Dec 7]; Available from: <a href="http://www.theaustralian.com.au/news/health-science/family-court-backs-parents-on-removal-of-gonads-from-intersex-child/news-story/60df936c557e2e21707eb198f1300276">http://www.theaustralian.com.au/news/health-science/family-court-backs-parents-on-removal-of-gonads-from-intersex-child/news-story/60df936c557e2e21707eb198f1300276</a>

Overington C. Carla's case ignites firestorm among intersex community on need for surgery. The Australian [Internet]. 2016 Dec 8 [cited 2016 Dec 8]; Available from: <a href="http://www.theaustralian.com.au/national-affairs/health/carlas-case-ignites-firestorm-among-intersex-community-on-need-for-surgery/news-story/7b1d478b8c606eaa611471f70c458df0">http://www.theaustralian.com.au/national-affairs/health/carlas-case-ignites-firestorm-among-intersex-community-on-need-for-surgery/news-story/7b1d478b8c606eaa611471f70c458df0</a>

<sup>&</sup>lt;sup>87</sup> Re Lesley (Special Medical Procedure) [2008] FamCA 1226

Sterilisation 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 self-determination. The alternative option of puberty blockers to support later self-determination appears not to have been examined.

### 7.4 Re: Kaitlin (2017)

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.<sup>88</sup>

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 require Family Court approval: 'At about age 12 or 13 she was prescribed testosterone in order to commence puberty' (at [6]). This was an inappropriate, forced intervention.

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.

### 7.5 Commentary

In her 2013 comments to the Senate inquiry on involuntary or coerced sterilisation, the Hon Diana Bryant, former Chief Justice of the Family Court, stated that:

<sup>88</sup> Re: Kaitlin [2017] FamCA 83.

I appreciate that the Committee may be contemplating scenarios whereby permission is sought to perform surgery on a young child to give them the appearance of one sex or another, without the child being of sufficient age and maturity to express a view as to the procedure. I am not aware though of judgment having been delivered in any such case before the Family Court.<sup>75</sup>

IHRA has seen no evidence that Court oversight has ever been sought for genital so-called 'normalising' surgeries. Clearly, however, such interventions occur without clinicians, governments, or parents seeking Court oversight, and the former Chief Justice and other Family Court justices have had ample opportunities to become aware of this failure of process and to comment on it. Such interventions are documented in medical histories in the 1993 case *Welfare of a Child A* cited by the Chief Justice in her comments to the Senate, and in the 2016 case *Re: Carla (Medical procedure)*.

It is also clear that, where such interventions are documented in the medical histories of children whose cases appears before the Court, no comment has ever been made by the Court questioning the suitability, appropriateness, indications, rationales, outcomes, or evidence for such prior medical interventions; or, in the case of *Re: Carla (Medical procedure)*, such interventions are described as having 'enhanced' genital appearance. This is deeply troubling.

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'.<sup>89</sup>

The Australian healthcare system appears to regard such interventions as unambiguously therapeutic due to parental distress and potential psychosocial stigma, even when they take place on healthy intersex bodies, or where clinical evidence supports monitoring gonads, even though such interventions contravene human rights norms established by multiple UN Conventions and the conclusions of a Senate inquiry.

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. 90

They also argue that the distinction appears to have been ineffective 'in stopping the number of non-approved sterilisations' of children with disabilities. <sup>90</sup> This is unsurprising when the Family Court has been willing to grant parental authority to consent to

<sup>&</sup>lt;sup>89</sup> Kennedy A. Fixed at Birth: Medical and Legal Erasures of Intersex Variations. UNSW Law Journal. 2016;39(2):813–42.

<sup>&</sup>lt;sup>90</sup> Kerridge I, Lowe M, Stewart C. Chapter 22: Children. In: Ethics and law for the health professions. Fourth edition. Annandale, NSW: The Federation Press; 2013. p. 582–604.

sterilisations of children. The authors also state that the Court process is expensive and cumbersome.

Further analysis of the cases *Re: Carla* and *Re: Kaitlin* is given in a forthcoming book chapter by co-executive director Morgan Carpenter, to be published by Intersentia, Cambridge (England).<sup>61</sup> A pre-print of that chapter has been supplied privately to the Commission head of publication with kind permission from editor Jens Scherpe.

### 8 Summary

- Medical interventions take place in pursuit of an arbitrary 'normality' that is not realised through surgery. These interventions are performed with impunity, without transparent human rights-based standards of care, and without effective, independent, human rights-based oversight. Such interventions do not meet established human rights norms.
- The Family Court system has not understood the intersex population, nor the nature of procedures in cases that it has been asked to adjudicate. Most cases are not subject to even this limited form of oversight.
- The Family Court system does not have a full range of clinical evidence put to it, in part because clinical practices are not grounded in evidence. This also means that proposed and actual interventions are experimental. Most cases concerning intersex children have had no effective contradictor. Even where discretionary child representatives have been appointed, they are apparently under no obligation to consult the child. Nothing in the Family Law Act (section 60CD) requires a judge to provide a child with an opportunity to give their views. Child representatives have failed to investigate the broader issues and have accepted a purely medicalised perspective reflective of only a section of the medical establishment. As noted in the Senate Committee Report and elsewhere, there is no clinical consensus regarding medical interventions. Concerns expressed over decades by intersex adults and organisations, by dissenting clinical voices, and by human rights institutions have wrongly been disregarded.
- The Family Court has failed to properly utilise its procedures in order to ensure that the best interests of intersex children have been thoroughly investigated and understood within the medical context, and within the human rights context.
- The 'best interests of the child' has been interpreted through a narrow lens, manipulated to facilitate experimental treatments that, contrary to Article 3 of the Convention on the Rights of the Child, conflict with the child's human dignity and right to physical integrity.<sup>18</sup> This has been facilitated through appeals to gender stereotypes and social norms with insufficient attention to the long-term health and well-being needs of the child.
- The cases of *Re: Carla* and *Re: Lesley* appear to show deliberate and unnecessary pre-empting of the legal capacity of a future adult, and the evolving capacity of a child. This appears to be a breach of existing principles.

### 9 Recommendations

- 1. The family law system must fully recognise the human rights of infants, children, adolescents and adults born with variations of sex characteristics, and must protect their rights, including their rights to bodily integrity.
- 2. The family law system must ensure that there is oversight to ensure protection of the human rights of infants, children, adolescents and adults born with variations of sex characteristics.
- 3. Family law legislation should prohibit deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants, children and adolescents. Such interventions should be deferred until the child has sufficient capacity to consent on their own behalf.
- 4. Any non-deferrable interventions which alter the sex characteristics of infants and children proposed to be performed before a child is able to consent on their own behalf should be identified as medical treatment outside the scope of parental consent and requiring authorisation of an independent body (hereafter referred to as the 'decision-making forum'). A decision-making forum must bring together human rights experts, clinicians, and intersex-led community organisations.
- 5. Whether consent is provided by the intersex minor or a decision-making forum, the pros and cons of medical treatment must be properly ventilated and considered, including the lifelong health, legal, ethical, sexual and human rights implications. Consent or authorisation for treatment must be premised on provision of all the available medical evidence on necessity, timing, and evaluation of outcome of medical interventions. Where there is no clinical consensus, this must be disclosed.
- 6. Where interventions are performed on intersex minors with capacity to consent, such consent must be fully informed, with individuals and families having access to funded, independent counselling and peer support.
- 7. Medical interventions must not be approved by the decision-making forum on the basis of rationales based on gender stereotypes, social norms or financial rationales. Interventions accompanying, following or reinforcing a sex assignment must never be based on technical considerations associated with surgery (for example, relative ease of construction of a vagina compared with relative difficulty of constructing a phallus).
- 8. To ensure adherence and transparency with these provisions, the decision-making forum should be advised, post facto (after the event), of the details of each case where informed consent and/or non-deferrable medical necessity have been asserted.

- 9. Consideration should be given to writing the International Covenant on Civil and Political Rights and the Convention on the Rights of the Child into federal law.
- 10. The current threshold criteria to determine whether or not a procedure is within the scope of parental authority is whether it is therapeutic or non-therapeutic. This criterion has failed to distinguish between interventions that are strictly clinically necessary and those that are not; between interventions based on culturally-specific social norms and gender stereotypes and those that are not. This criterion should be abandoned as a threshold test of whether a medical procedure requires oversight or authorisation from a decision-making forum.
- 11. Children born with variations of sex characteristics must be treated by multi-disciplinary teams. Multi-disciplinary teams must operate in line with transparent, human rights-based standards of care for the treatment of intersex people and bodies. Multi-disciplinary teams in hospitals must include human rights specialists, child advocates, and independent intersex community representatives.
- 12. Infants, children, adolescents and adults born with variations of sex characteristics must have resourced access to necessary and appropriate health, medical and allied services and treatment, including surgeries and hormone treatment, psychosocial, psychosexual and psychological support, and including reparative treatments. Standards of care must support reparative treatments. Treatment must not require conformity with stereotypical and clinical norms for female or male bodies, women and men, nor impose inappropriate psychiatric eligibility assessments.