



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

PO Box 46, Newtown, NSW 2042, Australia
+61 405 615 942 info@ihra.org.au
ihra.org.au

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Submission to the Australian Human Rights Commission on protecting the rights of people born with variations in sex characteristics in the context of medical interventions

1 Authors and endorsements

The submission was written by co-executive director Morgan Carpenter, M.Bioeth. (Sydney), with input from the board and members of Intersex Human Rights Australia, and from representatives of the AIS Support Group Australia and People with Disability Australia. Please contact morgan.carpenter@ihra.org.au or 0405 615 942 for further information or inquiries.

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: <http://ihra.org.au>.

This submission is endorsed by:

The **AIS 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: <http://aissga.org.au>

Disabled People's Organisations Australia ("DPOA"), 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 **LGBTI Legal Service Inc**, a Queensland non-profit community-based legal service: <https://lgbtilegalservice.org.au>

People with Disability Australia ("PWDA"), a national disability rights and advocacy organisation, and member of DPOA. 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: <http://pwd.org.au>

2 Introduction

We thank the Australian Human Rights Commission for this important and welcome opportunity to make a submission to the inquiry on protecting the rights of people born with variations of sex characteristics in the context of medical interventions.

Intersex people in Australia are routinely subject to medical interventions without personal informed consent, typically in infancy, childhood or adolescence. Intersex-led organisations including Intersex Human Rights Australia and the AIS Support Group Australia are aware of this through ongoing relationships and contact with intersex people, parents and family members, and clinicians. Much of this evidence is confidential. Published information can (and has) routinely been disregarded as anecdotal, as relating to “obsolete” clinical practices that took place “in the past” (without apology or redress), or as isolated incidents.

Clinical practices in relation to intersex people have historically relied upon a lack of transparency. In the latter half of the 20th century, this included a deliberate policy of concealment of diagnostic information in order to promote “normal” psychological development (Chase 1998; Conn, Gillam, and Conway 2005; Kirkland 2017). This still impacts upon community development, as well as affecting personal health and wellbeing. The NZ Office of the Privacy Commissioner has highlighted that progress in changing this paradigm is variable (Office of the Privacy Commissioner 2018). Lack of transparency and accountability, and unsubstantiated assurances of change, have prevented progress to ensure protection of the human rights of people born with variations in sex characteristics.

In recent times, we have become able to present incontrovertible evidence of current practices. These are described in Family Court cases cited in the Commission’s consultation paper (Australian Human Rights Commission 2018), in the *International Classification of Diseases* (Carpenter 2018c), and in research papers (Intersex Human Rights Australia 2018a; Carpenter 2018a). Data available suggest that hundreds of relevant surgeries happen each year (Carpenter 2018a). These practices continue despite a rhetoric of inclusion, recognition and support by governments for LGBTI populations, and also a series of guidelines, principles and statements by medical bodies and governments that have presented positions on human rights violations in medical settings, but which have been disregarded or co-opted. At the same time, the intersex human rights movement has become better organised, including in the development and signing of the *Darlington Statement*, a 2017 community consensus statement (Androgen Insensitivity Syndrome Support Group Australia et al. 2017).

In this submission we outline our responses to questions asked in the Commission’s consultation paper on protecting the rights of intersex persons/persons born with variations in sex characteristics in the context of medical interventions. We recommend a criminal prohibition of deferrable medical interventions, associated with transparent and accountable human rights-affirming oversight of relevant medical interventions and standards of care. We also call for resourcing and inclusion in all processes of affirmative, intersex-led peer support and systemic advocacy.

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4 Human rights and the principles we apply in this submission

4.1 UN Treaties and Treaty Body observations

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) (Attorney General's Department 2018), the Convention against Torture (CAT) (Carpenter and Organisation Intersex International Australia 2016; Committee against Torture 2017), the Convention on the Elimination of Discrimination against Women (CEDAW) (Intersex Human Rights Australia 2018b; Committee on the Elimination of Discrimination against Women 2018), the Convention on the Rights of Persons with Disabilities (CRPD) (Carpenter and Organisation Intersex International Australia 2017a; Committee on the Rights of Persons with Disabilities 2017) and the International Covenant on Economic, Social and Cultural Rights. Multiple UN Treaty Bodies have made observations or questioned clinical practices in Australia. Each report since mid 2017 has made stronger recommendations. We support these calls.

4.1.1 The *International Covenant on Civil and Political Rights*

Adopted in 1966 and in force from 1976, the *International Covenant on Civil and Political Rights* obliged ratifying member states, including Australia, to agree provisions relating to non-discrimination, protection from torture and experimentation, the right to liberty and security, the right to privacy, and the right to equality before the law. Each of these rights is engaged in relation to medical interventions on people born with variations in sex characteristics.

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 with Disability Australia (Carpenter and Organisation Intersex International Australia 2017b). The response cited 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):

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

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

such procedures constitute an absolute medical necessity (Human Rights Committee 2017).

4.1.2 The *International Covenant on Economic, Social and Cultural Rights*

This Covenant makes provisions in Article 12 for recognition of “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”, including “the healthy development of the child”. In mid 2017, the Committee on Economic, Social and Cultural Rights commented in the context of the right to health:

49. The Committee is concerned that children born with intersex variations are subject to early surgeries and medical interventions before they are able to provide full and informed consent (art. 12).

50. The Committee recommends that the State party study and implement the recommendations put forward in the 2013 Senate Community Affairs References Committee report on the ‘Involuntary or coerced sterilisation of intersex people in Australia’. (Committee on Economic, Social and Cultural Rights 2017)

4.1.3 The *Convention against Torture*

The *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment* provides for the elimination of “cruel, inhuman or degrading treatment or punishment”, including acts “committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity” such as in medical settings (United Nations 1984). In a 2013 report on abusive practices in medical settings that “may cross a threshold of mistreatment that is tantamount to torture or cruel, inhuman or degrading treatment or punishment”, Juan Méndez as special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment observed that “prohibition of torture is one of the few absolute and non-derogable human rights”, universally applicable, with a need for special protections for individuals from vulnerable or marginalised groups:

77. Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, “in an attempt to fix their sex”, leaving them with permanent, irreversible infertility and causing severe mental suffering ...

88. The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, “reparative therapies” or “conversion therapies”, when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups (Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment 2013)

In a list of issues prior to reporting for the Australian government in 2016, the UN Committee against Torture asked the following questions in relation to article 16:

24. In the light of the Committee's concluding observations (para. 20), please provide information on the efforts made towards prohibiting the use of sterilisation without the prior, free and informed consent of the person concerned in all Australian jurisdictions. Please also clarify whether non-urgent and irreversible medical or surgical treatment aimed at determining the sex of a child is permitted and performed on children and how does the State party guarantee that full, free and informed consent of the persons concerned is ensured. In this regard, please indicate what action has been taken by the State party to implement the recommendations of a 2013 Senate Community Affairs References Committee report on the involuntary or coerced sterilisation of intersex people in Australia. In addition, please indicate which criminal or civil remedies are available for people who have undergone involuntary sterilisation or unnecessary and irreversible medical or surgical treatment aimed at determining their sex when they were children and whether these remedies are subject to any statute of limitations (Committee against Torture 2016, 11).

As detailed in this submission, we understand that such medical interventions take place, without ensuring full, free and informed consent of the persons concerned, with no effective access to criminal or civil remedies.

4.1.4 The Convention on the Rights of Persons with Disabilities

The Committee on the Rights of Persons with Disabilities states that disability or “the existence of an impairment (including a physical or sensory impairment) must never be grounds for denying legal capacity or any of the rights provided for in article 12” on equal recognition before the law:

The denial of legal capacity to persons with disabilities has, in many cases, led to their being deprived of many fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty (Committee on the Rights of Persons with Disabilities 2014)

Further: “Support in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making” (Committee on the Rights of Persons with Disabilities 2014). Supported decision-making must be free of “undue influence”, including where there may be signs of fear, deception or manipulation.

General Comment 1 of the Committee reflects on the importance of autonomy, “respect for difference”, acceptance of “human diversity”:

reflects an interpretation of article 12 which is premised on the general principles of the Convention, as outlined in article 3, namely, respect for the inherent dignity, individual autonomy — including the freedom to make one's own choices —, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; and respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (Committee on the Rights of Persons with Disabilities 2014)

In General Comment 3, the Committee observes that:

32. Certain forms of violence, exploitation and abuse may be considered as cruel, inhuman or degrading treatment or punishment and as breaching a number of international human rights treaties. Among them are: forced, coerced and otherwise involuntary pregnancy or sterilization; any medical procedure or intervention performed without free and informed consent, including procedures and interventions related to contraception and abortion; invasive and irreversible surgical practices such as psychosurgery, female genital mutilation and surgery or treatment performed on intersex children without their informed consent (Committee on the Rights of Persons with Disabilities 2016)

The Committee states that this can occur through “Restricting or removing legal capacity”. In General Comment 6, the Committee describes discrimination as occurring “including in brutal forms such as non-consensual and/or forced systematic sterilizations and medical or hormone-based interventions ... denied access to health care, and mutilation and trafficking in body parts” (Committee on the Rights of Persons with Disabilities 2018, 2). The Committee also described how:

disability is a social construct and impairments must not be taken as a legitimate ground for the denial or restriction of human rights. It acknowledges that disability is one of several layers of identity (Committee on the Rights of Persons with Disabilities 2018, 2)

Human rights issues engaged by medical interventions on persons born with variations in sex characteristics also relate to article 17 on “protecting the integrity of the person”. Intersex and disability representative organisations have made submissions (including jointly endorsed submissions) to the Committee on the Rights of Persons with Disabilities. In a 2017 list of issues prior to reporting issued to Australia by the Committee, it asked, in relation to article 17:

*20. Please provide information on the measures taken to harmonize the legal frameworks at the national, state and territory levels that, in the absence of the free, prior and informed consent of the person concerned, prohibit the following:
(a) Sterilization of children and adults with disabilities;*

(b) Administration of unnecessary medical interventions, with particular attention to an individual's sexual and reproductive health and to people born with variations of sex characteristics (Committee on the Rights of Persons with Disabilities 2017).

4.1.5 The Convention on the Rights of the Child

Kirsten Sandberg, a member and former chair of the UN Committee on the Rights of the Child has written on the human rights issues engaged by discrimination and medical interventions on children born with variations in sex characteristics:

Children's rights are indivisible, and the Convention should be interpreted in a holistic way, meaning that the rights should not be seen separately or in isolation from each other. Four of its articles have been termed "general principles" by the Committee, which implies that they are cross-cutting and should be used in the interpretation and application of all the other articles. These are article 2 on the right to non-discrimination, article 3 no. 1 on the best interests of the child, article 6 on the right to life, survival and development and article 12 on the right to be heard. The right not to be discriminated against because of an intersex condition is a different issue from the question of whether or not a child should undergo surgery and other forms of treatment for its intersex condition. Other relevant CRC provisions are article 24 on the right to health, article 8 on the right to identity, article 16 on the right to private life, article 19 on protection from all forms of violence, and article articles 24 para. 3 on harmful practices (K. Sandberg 2018)

We make reference to these provisions throughout this submission, including reference to statements on preventing manipulation of the "best interests" test (Committee on the Rights of the Child 2013; Carpenter 2018a, 465), and a general comment on harmful practices, the *Joint general recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/general comment No. 18 of the Committee on the Rights of the Child on harmful practices* (Committee on the Elimination of Discrimination against Women and Committee on the Rights of the Child 2014). The Committee on the Rights of the Child has made the following recommendations to New Zealand in respect of harmful practices in our neighbour:

(b) Develop and implement a child rights-based health-care protocol for intersex children, setting the procedures and steps to be followed by health teams, ensuring that no one is subjected to unnecessary medical or surgical treatment during infancy or childhood, guaranteeing the rights of children to bodily integrity, autonomy and self-determination and provide families with intersex children with adequate counselling and support;
(c) Promptly investigate incidents of surgical and other medical treatment of intersex children without informed consent and adopt legal provisions to provide redress to victims of such treatment, including adequate compensation;

(d) Educate and train medical and psychological professionals on the range of biological and physical sexual diversity and on the consequences of unnecessary surgical and other medical interventions on intersex children;
(e) Extend free access to surgical interventions and medical treatment related to their intersex condition to intersex children between the age of 16 and 18 (Committee on the Rights of the Child 2016, 8).

In 2018, the Committee on the Elimination of Discrimination against Women has issued relevant concluding observations to Australia on this matter (Committee on the Elimination of Discrimination against Women 2018).

4.1.6 The Convention on the Elimination of Discrimination against Women

In mid 2018, the Committee on the Elimination of Discrimination against Women made strong observations, within the context of the *Joint general recommendation* with the UN CRC (Committee on the Elimination of Discrimination against Women and Committee on the Rights of the Child 2014). The Committee expressed concern at:

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

And called for Australia to:

26 ... (c) Adopt clear legislative provisions explicitly prohibiting the performance of unnecessary surgical or other medical treatment on intersex children before they reach the legal age of consent, implement the recommendations of the 2013 Senate inquiry on involuntary or coerced sterilisation of intersex persons, provide families with intersex children with adequate counselling and support, and provide redress to intersex persons having undergone medical treatment (Committee on the Elimination of Discrimination against Women 2018)

4.2 Senate Committee report on forced sterilisation

In 2013, the Senate Community Affairs References Committee conducted an inquiry on the involuntary or coerced sterilisation of people with disabilities. The inquiry additionally encompassed the involuntary or coerced sterilisation of intersex people. The committee conducted hearings, and received public and private submissions on the treatment of intersex people, including from legal and clinical bodies, and community organisations. The committee recommendations were agreed by cross-party senators. They include:

Recommendation 3

3.130 The committee recommends that all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should

favour deferral of normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons.

Recommendation 5

4.43 In light of the complex and contentious nature of the medical treatment of intersex people who are unable to make decisions for their own treatment, the committee recommends that oversight of these decisions is required.

Recommendation 6

5.30 The committee recommends that all proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court.

Recommendation 9

5.38 The committee recommends that the special medical procedures advisory committee draft guidelines for the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles. These guidelines should be reviewed on an annual basis.

Recommendation 10

5.41 The committee recommends that complex intersex medical interventions be referred to the special medical procedures advisory committee for consideration and report to whichever body is considering the case.

Recommendation 11

5.70 The committee recommends that the provision of information about intersex support groups to both parents/families and the patient be a mandatory part of the health care management of intersex cases.

Recommendation 12

5.72 The committee recommends that intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases. (Community Affairs References Committee, Senate 2013)

However, action to implement the recommendations has not yet been supported by the current Commonwealth government (Attorney General's Department 2015). 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". The government commended controversial and non-binding 2013 guidelines produced in the State of Victoria that we discuss below.

No Australian government has implemented recommendations from the 2013 Senate committee report. No governmental attempts at redress have been made in Australia. Further, the Family Court has authorised medical interventions that fail to meet

international human rights norms, and failed to address the human rights implications of medical interventions that have occurred without Court oversight.

4.3 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 (Androgen Insensitivity Syndrome Support Group Australia et al. 2017). It provides a statement recognising our heterogeneity as a population, 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.*

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 health needs persons old enough to have agency to express a non-normative sexual orientation or gender identity. Services for infants, children and adolescents with variations in sex characteristics, and services for parents and prospective parents, operate within profoundly pathologising frameworks. There are no specialist

medical 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 *Statement* makes additional comments about peer support that we cite later in this submission.

The *Darlington Statement* is consistent with a global intersex community statement: the 2013 *Malta Declaration (Third international intersex forum 2013)*. These community declarations are themselves grounded in ideas that human flourishing depends on our ability to respect human diversity. These include ideas that both respect individual self-determination, and also acknowledge and encourage community development and engagement with peers.

4.4 The Yogyakarta Principles plus 10

We are also guided by the *Yogyakarta Principles* (Yogyakarta Principles 2007) and the *Yogyakarta Principles plus 10* (Yogyakarta Principles 2017). 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; and Chris Sidoti, international human rights specialist and former Australian Human Rights Commissioner (1995-2000); and Morgan Carpenter, a co-executive director of IHRA.

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 children from unconsented and non-urgent modifications to their sex characteristics (Malta 2018). This is, broadly, a model we wish 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. (Office of the High Commissioner for Human Rights et al. 2016)

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 (Australia 2015). 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 *Yogyakarta Principles plus 10* also recognise 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 other populations. 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.

4.4.1 Principle 32: The Right to Bodily and Mental Integrity

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' 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;*
- 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.*

4.4.2 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 (Orentlicher and Economic and Social Council 2005; World

Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance 2001). The *Principles* 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;*
- 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;*

1) 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

4.4.3 Additional obligations

The *Yogyakarta Principles plus 10* also applies the concept of “sex characteristics” to the non-discriminatory utilisation of prenatal and genetic selection and modification technologies, to reasonable accommodations (reasonable adjustments), and to the rights to education, information and health (Yogyakarta Principles 2017).

5 Terminology

5.1 Question 1: Terminology

“Is the term ‘people born with variations in sex characteristics’ appropriate, or is there a better way to describe the people who are the subject of this Consultation Paper?”

Here we distinguish the words used to describe the population that are the subjects of this consultation, from the terms needed to achieve legislative and regulatory change by means of this consultation and its outputs.

5.1.1 Describing the population

We refer to people who are subjects of this Consultation Paper as intersex people, or people with intersex variations, and also as people born with variations of sex characteristics. We use the term intersex 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 (Office of the High Commissioner for Human Rights et al. 2016).

This term has been employed consistently in jurisprudence and statements by human rights institutions around the world, including UN Treaty Bodies, European, African and InterAmerican regional bodies (for example, Office of the High Commissioner for Human Rights et al. 2016), and national institutions in Europe, Argentina (Mouratin and Instituto Nacional contra la Discriminación, la Xenofobia y el Racismo 2015), Kenya (Kenya National Commission on Human Rights 2018), New Zealand (Human Rights Commission New Zealand 2018) and elsewhere. To reject this term is to untether discussion of the lived experience and human rights of intersex people in Australia from discussions elsewhere. Indeed, a clinical adoption of “disorders of sex development” in the “Consensus statement on

management of intersex disorders” (Hughes et al. 2006) arguably had such a purpose. As Georgiann Davis states:

This shift allows medical professionals to reassert their authority and reclaim jurisdiction over intersexuality in light of intersex activism that was successfully framing intersexuality as a social rather than biological problem (Davis 2011).

We use the term intersex to include all people born with variations of sex characteristics; that is, bodies that do not fit medical or social norms for male or female bodies. In doing so, we acknowledge and respect the diversity of intersex people in terms of our identities, legal sexes assigned at birth, our genders, gender identities, and the words that individuals use to describe our bodies. We recognise intersex people “as part of human diversity and humanity” (United Nations 2006). We seek to eliminate violence, harmful practices, stigma, misconceptions, and other barriers to our full and equal participation in society.

We recognise contention about the term intersex. In our view, contention about the word is a symptom of stigma and discrimination, and not its cause. Contention regarding language is common to many, potentially all, stigmatised populations, for example, individuals may be people with disabilities or disabled people; gay, queer, lesbian, or use other terms; transgender, gender diverse, transsexual, sistergirl, fa’afafine; Indigenous, First Nations, Aboriginal, Torres Strait Islander, or use other terms. These terms are associated with stereotypes about each population, and these are in all cases the sources of misconceptions, and frustration. On the one hand, Miranda Fricker describes how stereotypes can limit our understanding of ourselves, and even influence behaviour:

Take our pre-suffrage, politically minded woman again. Her experience of persistent testimonial injustice in respect of matters political might well, in the absence of community, not only help rigidify what sort of social being she is allowed to count as ... Stereotypes make themselves felt in the form of expectations, and expectations can have a powerful effect on people's performances (Fricker 2007, 55–56).

It is because of narrow, normative ideas about what it means to be female or male that the identities of intersex people are called into question. There are numerous Australian examples of assumptions about identity, and consequential reassignment of sex.

In a paper in the *Australian Law Journal*, Bailey (1979) described as “sex-change surgery” the surgical interventions consented to as an adult by the man, assigned male at birth, who was the subject in the Family Court case *In the marriage of C and D (falsely called C)*. Mike O’Connor stated in 2016 that “feminising” surgery was a “reassignment” in “a true hermaphrodite”:

In 2013, a United States Federal Court held that non-consensual genital and gonadal surgery may violate the constitutional rights of affected children. The claim concerned MC, a 16-month-old male infant born in South Carolina in 2004. The boy was a true hermaphrodite, possessing an ovotestis and was subjected to

reassignment surgery (a feminising genitoplasty) involving amputation of the penis and removal of testicular tissue. (M. O'Connor 2016)

Fears about the word intersex, common in some parent-led groups, is often a reaction to misconceptions, but also a fear of what Miranda Fricker describes as the self-fulfilment of prejudicial stereotypes:

prejudice operating against the speaker may have a self-fulfilling power, so that the subject of the injustice is socially constituted just as the stereotype depicts her (that's what she counts as socially), and/or she may be actually caused to resemble the prejudicial stereotype working against her (that's what she comes in some measure to be). (Fricker 2007, 54–55)

Regarded and treated as people who do not fit medical and social norms for sex and gender, and even as people undergoing early “reassignment”,¹ it is no surprise that intersex people think about concepts of sex and gender in ways that most people may never do. A 2006 clinical “consensus” statement regards as a rationale for early surgery “mitigating the risks of ... gender-identity confusion of atypical genital appearance” (Houk et al. 2006). However, this is a circular argument. Iain Morland observes:

it is possible that the highly unusual experience of genital surgery could make anyone uncertain, to some extent, about their gender (2011, 152)

This possibility has thus served as a rationale for concealment of diagnostic and other medical records (Holmes n.d.). Morland also observes that post-surgical “certainty about genitalia” does not foreclose uncertainty about gender (Morland 2011, 151). Georgiann Davis, the president of the US AIS support group AIS-DSD comments, in relation to the opening up of that organisation in 2014-2015 to intersex people who identify with genders other than female:

there is often resistance to organizational change by organizational members who have been psychologically and unethically harmed by medical professionals who frame intersex as a medical emergency rather than a natural bodily variation... The concern was that intersex women needed their own space, and if membership were opened to all gender identities and not just those who identify as women, current members would feel their gender authenticity questioned.

These are reasonable concerns given how society stigmatizes those with bodies that defy normative sex and gender expectations (i.e., women who have internal testes but an outward female appearance). Medical professionals often frame the presence of intersex as a medical pathology rather than a natural bodily variation, and this fuels parental fears about their child's gender identity (Davis 2018)

¹ See, for example, later discussion in relation to the model law on female genital mutilation.

Parents may not want sex and gender norms or stereotypes interrogated, especially where these might call a child's history of medical interventions into question.

In a paper for the Australian government sports inclusion project *Play by the Rules*, Morgan Carpenter comments:

The words we know and use to describe our bodies also vary widely, depending on our experiences of medicalisation and medical interventions, disclosure of this information to us, and also in response to stigma and misconceptions. Some people may be unaware of the word or its relevance to them, because of either the medicalised ways that their bodies have been described to them, or associations of intersex with LGBT populations. Other people may not use the word intersex because it has borne the weight of public misconceptions about our bodies and identities, but fundamental concerns about regulations of bodies affect all of us nonetheless. (Carpenter 2018d)

On the other hand, accepting a word (and the role of stigma in promoting misconceptions) can be a source of community and self-affirmation. To a significant extent, if we adapt the definition of the "social model of disability" acknowledged by the UN, People with Disability Australia (2018) and other institutions, to identify a "social model of intersex", then we can accept that misconceptions are social, attitudinal and communication barriers that must change to enable people born with variations of sex characteristics to participate in society on an equal basis with others. The social model of disability can itself be applied directly to the situation of persons born with variations in sex characteristics.

The causes of stigmatisation and discrimination do not lie in the words people use, but they can instead be found in narrow normative ideas about what it means to be female or male. Thus, while Australian sociological research on the needs of 272 people born with atypical sex characteristics found that 60% used the word intersex in some form or another, 77 participants described experiences of bullying at school:

Bullying varied from occasional rude questions which the participant tried to dismiss to name-calling and more regular insults (like 'dyke' or 'boy-girl') which were harder to ignore. It also sometimes included physical violence requiring staff or family intervention, which participants sometimes said caused them to drop out of school or consider suicide. Perpetrators were mainly students but occasionally staff. Sometimes the bullying was directed on the basis of a known variation; more often it was on the basis of unusual traits (such as tallness or shortness, lack of energy, lack of development, learning disorders or various sex characteristics) or treatment (and subsequent time off school) related to participants' particular variations (T. Jones 2016).

Irrespective of the words we use, and even irrespective of the words we know and understand ourselves, fundamental concerns about the regulation of bodies born with variations in sex characteristics affect all of us.

We also recognise that some misconceptions, including arguments that intersex is an identity, and sometimes specifically a gender identity, serve particular interests. On the one hand, many individuals frame LGBTI issues within an identity framework. Discussions about LGBTI populations typically assume that LGBTI persons are adults, or older children, with agency to express their identities. The reality is that intersex persons are united not by a shared identity, sexual orientation or gender identity, but instead by common experiences of stigma, discrimination and violence due to our innate sex characteristics. While inappropriate, such assumptions appear to us to reflect a degree of naivety and complacency.

On the other hand, within clinical contexts, intersex as identity can be deployed to distinguish and maintain authority over bodies that innately defy sex and gender norms (Carpenter 2018a, 488). Yet medical interventions are intended to construct normative identities. A 2006 clinical summary “consensus statement” states that claimed “rationales for early reconstruction” include “mitigating the risks of ... gender-identity confusion of atypical genital appearance” (Houk et al. 2006, 755). Indeed, the Senate committee report, in 2013, observed:

3.109 As OII commented, normalisation surgery is more than physical reconstruction. The surgery is intended to deconstruct an intersex physiology and, in turn, construct an identity that conforms with stereotypical male and female gender categories (Community Affairs References Committee, Senate 2013)

We are also aware that clinicians may argue in favour of DSD as a more “precise” term. This fails to recognise that DSD is similarly lacking in precision. There are at several issues here, and we address these below.

5.1.1.1 Many different versions of “DSD”

Firstly, the term itself lacks standardisation, being imprecise in use:

- It was introduced in the clinical so-called “Consensus statement on management of intersex disorders” as “disorders of sex development” (Hughes et al. 2006).
- The term is frequently frames as “disorders of sexual development” (for example, Wunsch 2012; Deans, Berra, and Creighton 2010)
- Sydney Children’s Hospital Network and others have employed the term “disorders of sexual differentiation” (Topsfield 2018; Shawky and Nour El-Din 2012).
- A Family Court judge has described a “DSD” as a “sexual development disorder” (Family Court of Australia 2016), highlighting the similarity of the concept to the disordering of sexual orientation and sexual identity (Carpenter 2018c)
- Some individuals have attempted to reframe DSD as “diverse sex development” (L.-M. Liao and Simmonds 2013)
- Some organisations have reclaimed the term as “differences of sex development” (Human Rights Watch 2017). We are wary of such changes, as “DSD” can be interpreted as meaning any of the above terms.

5.1.1.2 *Boundary disputes in medical opinion*

Secondly, the boundaries of the term are imprecise and subject to contention (we note here that this is an argument against the term intersex):

Some clinicians propose to remove diagnoses from the DSD umbrella (González and Ludwikowski 2016); we believe that a key rationale for such developments is the maintenance of clinical authority over surgical practices affecting children so diagnosed.

5.1.1.3 *Boundary disputes in medico-legal opinion*

Thirdly, while the intersex population and transgender populations have differential access to medical interventions (i.e. trans persons have restricted access to interventions), the term DSD, and any other term with the same purpose, have the same perceived benefits as the term intersex to some people who seek access to medical interventions that are imposed on intersex people. An example is evident in the words of a member of the legal issues committee of the World Professional Association for Transgender Health (World Professional Association for Transgender Health 2018), and a founder of its Australian and New Zealand branch. Rachel Wallbank has commented:

Transsexualism [is] a naturally occurring form of diversity in human sexual formation and a form of intersexual disorder of sexual development with a clearly therapeutic medical treatment protocol and not a mental disorder or a psychological phenomenon. (National Foundation for Australian Women and The University of Melbourne 2016)

Transsexualism is an intersex condition and a disorder of sexual development therapeutically medically treated by hormonal therapy and Genital Reassignment Surgery (Wallbank 2015)

Such perspectives separate the term intersex from its history, substitute a different human rights agenda and movement, and have no regard for the consequences. They have adversely impacted community organising over many years.

5.1.1.4 *Non-acceptance of “disorders of sex development”*

Finally, widespread non-acceptance of the term “disorders of sex development” by individuals born with variations of sex characteristics, and consequences for utilisation of health services, means that there is debate about the future of the term (Delimata et al. 2018; Carpenter 2018c). The next international clinical “I-DSD” conference, on 4-6 July 2019, will debate the term (University of Glasgow 2018). It is important, then, that clinical language is not used to describe the population, not only on grounds that it reasserts medical authority over a social issue, but also that it changes over time.

5.1.2 Intersex and new sex classifications²

IHRA and the AISSGA support the *Darlington Statement* (2017), based on a global community declaration known as the *Malta Declaration* (Third international intersex forum 2013), which support universal access (by intersex and non-intersex people alike) to non-binary and alternative sex classifications. More significantly, the creation of new sex categories is not a long-term goal of the movement; both documents call for an end to the inclusion of sex or gender on official identification documents. These calls reflect the diversity of sex assignments and gender identities held by intersex people in Australia and internationally, and risks that arise from associating singular sex classifications with a diverse population (T. Jones 2017; Johnson et al. 2017; Intersex Human Rights Australia 2016).

Medicine has long since instrumentalised such developments, albeit selectively. Some parties to the 2006 “Consensus statement on management of intersex disorders” sought to differentiate between identity terms and biological characteristics in response to third legal categories (Carpenter 2018a). Such clinical responses do not date back to a 1979 Family Court judgment that we describe below; the Court annulled the marriage of an intersex man, describing him as a hermaphrodite unable to marry in Christendom – an ahistorical perspective (Finlay 1980; Family Court of Australia 1979; Carpenter 2018a). Clinical responses instead took place at a time in the early 2000s when medical interventions were vigorously contested, and intersex was being successfully (and accurately) framed as a social issue (Davis 2011; Carpenter 2018a). The resulting 2006 clinical consensus statement nevertheless supported surgical attempts to “mitigate” perceived identity issues (Houk et al. 2006) despite an absence of evidence (Zillén, Garland, and Slokenberga 2017; Carpenter 2018a).

New medical guidelines published by the International Association of Athletics Federations (2018) on the eligibility of female athletes with “differences of sex development” remark that legal classifications “other than simply male and female” now exist “As a result” of the existence of “differences of sex development, or **DSDs**” (2018, 1). The clinical regulations mainly target women with intersex variations from resource-poor regions with limited healthcare provision who may not have been subjected to forced medical interventions (Karkazis and Jordan-Young 2018). Karkazis and Carpenter state:

The regulations deploy an outdated interventionist clinical framework, enforcing narrowed gender norms but now accommodating a third sex as punishment for those who resist medicalization of their bodies (Karkazis and Carpenter 2018, 7)

5.1.3 Commission role in relation to terminology

It is not the Australian Human Rights Commission’s role to determine terminology. It is not necessary for the Commission to propose or utilise one single term to describe the

² For more analysis on intersex people and sex classifications, see our May 2018 submission to the Australian Law Reform Commission at <https://ihra.org.au/32111/alrc-may-submission/>

population in all contexts. It is also not the role of clinicians to determine terminology for the intersex movement.

Given the use of different terms in different contexts both within Australia and outside Australia, it is essential to acknowledge the many different terms used by individuals with variations in sex characteristics for substantively the same concepts, that people are born with sex characteristics that do not fit medical (and sometimes social) norms for female or male bodies.

We welcome and acknowledge the vital importance of international human rights jurisprudence on intersex people, including jurisprudence emanating from UN Treaty Bodies and the Office of the High Commissioner for Human Rights, and that emanating from regional bodies and in the *Yogyakarta Principles plus 10*. It is essential that all reports and statements that arise out of the Commission's inquiry maintain a connection to that jurisprudence.

We seek to end the stigma that intersex people experience, including misconceptions and stereotypes in relation to the term itself. At the same time, we acknowledge a need to utilise terminology in legal and regulatory contexts that cannot be misrepresented and that applies to all individuals irrespective of the terminology that they prefer. We support the use of universal terms like "sex characteristics" in legal and regulatory contexts, and definitions of relevant populations using the expressions "variations in sex characteristics" or "variations of sex characteristics".

5.1.4 This consultation

Despite favouring use of the term intersex, for reasons stated above, we support the framing of this inquiry by the Australian Human Rights Commission on "people born with variations in sex characteristics".

This framing avoids gaps and inconsistencies created by assumptions prevalent in LGBTI contexts that intersex people are an identity group, and it (at least seeks to) avoid misconceptions about the population so described.

This framing also avoids gaps and inconsistencies that arise from use of specific clinical diagnostic terms of the moment, and futile, narrow clinical discussions about which diagnoses qualify as intersex or not that serve primarily to maintain the status quo; a status quo that has provoked the Commission inquiry. These attempts disregard Australian legislative definitions, and definitions in use by the UN and other human rights institutions. In doing so, these discussions may serve simply to minimise transparency regarding clinical practices and attempt to maintain clinical authority over decision-making regarding the treatment of as many populations as possible.

Like the consultation exercise, we believe that any reform that singles out intersex people/people born with variations of sex characteristics for protection must carefully

ensure that definitions cannot be gamed or misinterpreted as referring to people with particular sex classifications or people with what may be interpreted as identity labels.

As a consequence, we believe that the study framing has practical utility in the construction of legal and regulatory frameworks to protect the human rights of people born with variations of sex characteristics in the context of medical interventions.

We recommend defining “sex characteristics” using the model text offered in the *Yogyakarta Principles plus 10*. This definition focuses on body parts, and not legal classifications. It has potential utility to multiple populations, including in relation to elective medical procedures, female genital mutilation.

A definition of sex characteristics can also be utilised, as in a UN definition, to define “variations of sex characteristics” (Office of the High Commissioner for Human Rights et al. 2016). Such a definition must not be pathologising.

5.1.5 The universality of human rights

Human rights are universal, so we believe that the recommendations offered by the Commission in a report subsequent to this consultation will have utility to all people irrespective of their sex characteristics, in relation to modifications to those characteristics. In relation to this, in his position as United Nations High Commissioner for Human Rights, Zeid Ra'ad Al Hussein stated in 2015 that:

All human beings are born equal in dignity and rights. Those foundational, bedrock principles of universality and equality mean that all of us, without exception, and regardless of our sex characteristics, are equally entitled to the protections of international human rights law. (United Nations High Commissioner for Human Rights 2015).

This universality is expressed in Principle 32, ‘The Right to Bodily and Mental Integrity’ of the *Yogyakarta Principles plus 10*, which we commend to the Commission. Child Rights International Network, a network that support the UN Convention on the Rights of the Child, has also published a statement on children’s bodily integrity:

Of particular concern are the practices that enjoy majority support or indifference within the countries in which they’re practiced. These are the hardest to root out and expose as harmful to children because it would entail disturbing the status quo. Some of the most abhorrent violations of children’s bodily integrity of our time — which are still widely upheld in practicing communities — are those carried out for no medical reason on the most sensitive and private part of the human body: the genitals.

These include female genital mutilation, forced sex assignment of intersex children, forced or coerced sterilisation of children with disabilities, and routine male circumcision. (CRIN 2018)

Similar ethical positions are taken by ethicists like Brian Earp, Lauren Notini, and Rebecca Steinfeld (Carmack, Notini, and Earp 2015; B. Earp 2016; B. D. Earp 2016; B. D. Earp, Hendry, and Thomson 2017; B. D. Earp and Steinfeld 2018; B. Earp and Steinfeld 2017; Shahvisi and Earp 2018; Svoboda 2013). These essentially take the position that persons able to personally give informed consent can decide to do whatever they wish to modify their sex characteristics, but that children should be protected from decisions other than those based on strict interpretations of medical necessity. For example, Earp and Steinfeld state:

The emerging consensus among scholars in these fields is that the ethics of nontherapeutic genital cutting (NGC) should hinge, not on the apparent sex of the subject—as judged by their external genitalia— but rather on considerations of medical necessity, informed consent, and respect for the bodily autonomy of all persons (B. Earp and Steinfeld 2017).

To summarise the argument, ethicists firstly question distinctions based on sex or gender as discriminatory: there is physical and symbolic overlap between individuals (leading to definitional questions), and there is no principled or coherent way to systematically distinguish childhood interventions. Secondly, ethicists support distinctions based on autonomy and informed consent. Such distinctions are also pragmatic, given the desire of some adults for genital surgeries, including labioplasties or vulvoplasties.

In NSW, female genital mutilation is prohibited while cosmetic female genital cutting is permitted, as are medical interventions on infants, children and adolescents with variations of sex characteristics and routine male circumcision. However, the latter is no longer supposed to be performed in public hospitals. Sydney Children’s Hospital Network observes that:

Ethical and human rights concerns have been raised regarding routine infant male circumcision. This is because it is recognised that the foreskin has a functional role, the operation is non-therapeutic and that the infant is unable to consent (Sydney Children’s Hospital at Westmead, Sydney Children’s Hospital, Randwick, and Kaleidoscope Children, Young People and Families 2015)

Nevertheless, the hospital network also states that parents should be able to “weigh the benefits and risks” despite observing these concerns.

It is our view that no single group should be singled out for cosmetic or other medical interventions that are not supported by strict and evidenced interpretations of non-deferrable medical necessity. To ensure adherence to this principle, we seek effective independent oversight.

Nevertheless, we accept that it is appropriate to limit the scope of any proposed regulation and legislation to the scope of this inquiry; that is, to people born with variations of sex characteristics.

This population should be defined solely in relation to physical characteristics. This population should be defined as widely as possible to minimise the risk that it will be circumvented through change to clinical terminology.

6 Understanding lived experiences

6.1 Question 2: Medical experiences

“Broadly, how would you describe your experiences in the context of medical interventions?”

This submission is an organisational submission. The experiences of many members of IHRA and AISSGA are routinely dismissed as related to practices “in the past”, despite a lack of apology and redress. Much of our current knowledge is limited to confidential contexts, and we hope that a diverse range of people born with variations in sex characteristics and their families have spoken to the Commission to provide first-hand accounts. We have promoted participation in the consultation, without in any way dictating or limiting the kinds of contributions that individuals might wish to make. We are aware, however, that to tell our personal stories is to revisit trauma and, while the Commission’s process has facilitated short-term access to psychological support, this will limit disclosure.

This submission utilises published and public discussion on issues raised in connection with the consultation, and we have endeavoured to focus on issues of current relevance, including current and recent materials, accompanied by some historical analysis.

6.2 Questions 3 and 4: Data sources

“What are the current Australian sources of information and education about the experiences of people born with variations in sex characteristics?”

“Are there gaps and/or inconsistencies in sources of information and education that are available about the experiences of people born with variations in sex characteristics? If so, what is the impact of this?”

6.2.1 Clinical data

There is little evidence or transparency regarding historic and current clinical practices. This means that assessments about which practices are “in the past” and which are in the present are not available to us: we neither have a clear and comprehensive understanding of past practices nor a clear understanding of present practices.

Numerous journal articles and submissions to prior inquiries identify clinical perspectives on the experience of people born with variations in sex characteristics. The oldest Australian clinical journal article we have so far identified is an article in the *Medical Journal of Australia* in 1966. The article, “Hermaphroditus Verus, with Report of a Case” is notable not only for its description of how clinical practices had then changed such that early surgeries

became the norm, but also for identifying that persons not subjected to such surgeries could and did, “As often happens”, grow up to be accepted by family and individuals:

A's parents were told at his birth that he was a male, and that his gross phallic deformity [sic] could not be corrected until he was 16 years old. No doubt this advice was tendered by a disciple of the then popular but now rarely used method of delaying definitive treatment of hypospadias, with the use of an inlay graft, until the patient was approaching adult life. As often happens in such cases, by the time he was 16 years old the deformity [sic] had become so accepted, by both the parents and the patient, that no steps were taken to commence reparative surgery. In the meantime, he had led a normal life at school and had now commenced work. He continued to remain undisturbed by his physical defects [sic] for some years, but, when he was 21 years old, he consulted his local medical practitioner because of attacks of periodic abdominal pain..." (Fraser, O'Reilly, and Rintoul 1966)

Hypospadias was, then, regarded as something that could be left until the individual approached adulthood, as a matter of clinical choice or ideology, with outcomes that are not distressing to the individual or family. It is the clinicians in this journal article who framed A's body as deformed. It is mirrored in a 2016 claim by Mike O'Connor that doctoral research in the 1950s by John Money on 250 children who did not undergo genital surgeries found that “the vast majority grew into well-adjusted adults” (M. O'Connor 2016). It so happens that the subject of the *Medical Journal of Australia* article underwent surgeries to make his body more typically male, as was rightly his choice, beyond issues relating to abdominal pain.

It is distressing that this man's later marriage was annulled, in 1979 by Bell J, in the Family Court of Australia, on the ahistorical basis that he was not a man but a “true hermaphrodite” and a combination of male and female (Family Court of Australia 1979; Finlay 1980).

A 2006 clinical “consensus statement” focused on justifications for early medical interventions, rather than data. Morgan Carpenter comments:

the manifest goal appears to have been to provide rationales for medical intervention, but not to question or substantiate their underlying principles, so the Consensus Statement did not lead to systematic collection of evidence, nor longitudinal or comparative research on outcomes... [A] lack of clinical consensus identified by Australian Senators in 2013 has since also been summarised succinctly by a 2016 global update to the earlier clinical 'Consensus Statement'. (Carpenter 2018a)

Some limited clinical data appears in journal articles by clinicians in Victoria and New South Wales (for example, Hewitt and Warne 2009; Warne and Hewitt 2009; M. O'Connor 2016), in news articles (Bock 2013; Topsfield 2018), and in submissions to the 2013 Senate committee inquiry on the involuntary or coerced sterilisation of people with disabilities (Australasian Paediatric Endocrine Group et al. 2013; Royal Children's Hospital Melbourne

2013). Australian clinical studies are based on small cohorts of individuals who have been researched by the treating hospital. They lack independence and suffer from sample bias, selection bias, low participation rates and clinical framings on clinical preoccupations (for example, with post-surgical genital appearance). Reports from international studies have been cherry-picked and, in some instances, demonstrate subjects' inability to provide informed consent to clinical interventions performed on the basis of partial data and clinical opinion (Baratz and Feder 2015; Carpenter 2018a). In contrast, non-clinical studies have been dismissed as politically motivated (for example, Meyer-Bahlburg 2005). In general, a dismissal of criticism can be regarded as unscientific.

There has been no historical attempt to construct a clinical reference group of Australian elders with intersex variations; those, like the man in the *Medical Journal of Australia* and Family Court case, who have not been subjected to routine early medical interventions.

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 Age* in 2013 that it performs 10-15 'genital reconstruction operations a year often on girls under the age of two' each year (Bock 2013).

In 2016, O'Connor reported in the *Journal of Law and Medicine* that 13 cases were taken to a DSD Forum in the year 2014-2015:

In Sydney, for example, there is one DSD Forum for the two children's hospitals. This advisory group comprises paediatric endocrinologists, urologists, gynaecologists, psychologists, geneticists, ethicists and representatives of the hospital executives. The Forum reviews cases of DSD where there may be an ethical question in the child's management (eg gender of rearing, gonadectomy, genital surgery). Across the two centres, in 2014-2015, 13 cases were brought to the Forum. No patients have had gender reassignment based on Forum outcomes. Most referrals have been for gonadectomy for malignancy risk (eg 45XO/46XY females with non-functioning ovaries who are about to commence growth hormone therapy for short stature). Severely virilised females with CAH are also reviewed with regard to early versus late clitoral reduction and vaginoplasty. The parents' and child's point of view is taken into account in all cases (M. O'Connor 2016, 538).

This statement presupposes that surgery will happen (either early or late), and the role of parents as well as children appears secondary. The idea of reassignment is unclear – O'Connor uses this term in his paper refer to initial assignment, alternatively it may refer to a later actual reassignment. In 2017, Wang and Poppas reported that rates of repeat or revision surgeries following an early vaginoplasty were as high as 75% but are more recently "3-36%":

After early (prepubertal) vaginoplasty, many CAH patients develop vaginal stenosis [narrowing] and require vaginal dilation (only after puberty), revision

vaginoplasty, and sometimes multiple reconstructive procedures (Wang and Poppas 2017).

More broadly, 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. In a submission to the religious freedoms inquiry, Morgan Carpenter summarised as follows:

2014 Department of Health Medicare Benefits Schedule Review on “vulvoplasties”³ 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 (Carpenter 2018b).

In a book chapter published in September 2018, Morgan Carpenter comments:

In summary, these data indicate possibilities of delay to vulvoplasties, and a marginal reduction or displacement to other codes of ‘procedures for anomalies of genitalia’, but they do not support claims of clear or systemic change to clinical practices in Australia (Carpenter 2018a).

6.2.2 A policy of concealment

Medical practices have, from the point where surgical interventions became the norm – and may still currently – be grounded in a model of concealment. This has direct consequences for the availability of a population for clinical and other research. In 1998, Cheryl Chase discussed what Kipnis and Diamond consider an ‘epistemological black hole’ that Chase notes ‘precludes follow-up of intersex surgeries’:

³ Defined in the Review as ‘any surgery performed on the outside female genital structures’ thereby including labioplasties and clitorectomies

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 (Chase 1998).

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. (Office of the Privacy Commissioner 2018)

Australia and New Zealand share medical and clinical associations, such as the Australasian Paediatric Endocrine Group, 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.

It is not coincidental that, as late as 1993 (the year the first intersex advocacy organisation was formed), clinicians claimed that no patients had complained ‘even when the entire clitoris had been removed’ (Edgerton 1993) while other clinicians reported how they “spend hours educating these parents” (Hendricks 1993). Just three years later, claims that complainants were “zealots” and “the unhappy ones” appeared in the *New York Times* (Angier 1996). Such claims persist (Australasian Paediatric Endocrine Group et al. 2013). Morgan Carpenter describes this as a form of testimonial injustice, where “the credibility of intersex voices is diminished, even where they speak about personal lived experience, and even though contrary perspectives lack evidence” (Carpenter 2018a).

The argument that “some people are happy with their surgery” presupposes idea that there are two dichotomous groups: a group that favours surgery and a group threatening to take those surgeries away. This is a straw man argument. The argument is not for or against surgery, it is for consent and choice, through deferring non-medically necessary surgeries until people can decide for themselves if or what surgeries they wish to undergo.

The idea that some people are happy could mean that such individuals are lucky not to experience what the clinician Australasian Paediatric Endocrine Group has described as “particular concern” regarding post-surgical sexual function and sensation (2013).

More broadly, claims that this is common or widespread neglect to consider the impact of – and variable to – the historical model of concealment of diagnostic and related information from subjects of early surgical interventions. The impact is that most intersex people do not

know their medical history, and do not have language to describe their body or history. Individuals are still discovering the truth, over time. As a consequence, most people born with intersex variations simply don't have agency.

For those individuals aware of aspects of their medical history, the construction of many relevant medical diagnoses as rare, almost vanishingly rare has a quelling impact on the extent to which people can explore, consider, critique, share, dialogue or express their feelings about their diagnoses or histories. The ubiquitous emphasis on rarity reiterates the message of freakery, shame and silence. Individualisation of diagnoses also has an impact on the perceived relevance of cross-diagnosis peer support.

The argument that some people are happy with genital cutting is also made in relation to female genital mutilation. In societies where female genital mutilation is a norm, it may perform a role as a rite of passage, create a sense of belonging, and subjects of female genital mutilation may pressure others to undergo the procedures (World Health Organization et al. 2008). This harmful practice may be portrayed as beneficial to its subjects. This doesn't make the practice acceptable.

While some clinical centres have asserted that they no longer conceal diagnostic information, we fear that information provision may remain overly pathologised, partial, and not present accurate representations of community organisations.

6.2.3 Disclosure of practices during the 2013 Senate inquiry

The Senate inquiry process documented many current medical practices and rationales, understood to be reflected in a public submission to the inquiry by the Australasian Paediatric Endocrine Group. 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.
(Australasian Paediatric Endocrine Group et al. 2013)*

We discuss these rationales in a later section.

6.2.4 Population data

Schneuer and colleagues have conducted a range of studies on the impact of specific diagnoses or medical interventions on children's development at school.

A large-scale study of 211,978 children in NSW found that children "exposed to general anaesthesia before 4 years have poorer development at school entry and school performance":

Although the risk for being developmentally high risk and poor reading attenuated for children with only 1 hospitalization and exposure to general

anesthesia, the association with poor numeracy results remained. (Schneuer et al. 2018).

In the US, the FDA has issued a warning about exposing young children to general anaesthetic (Center for Drug Evaluation and Research and Food and Drug Administration 2016).

These are serious concerns that need to be fully taken into account in the context of this study. A 2015 sociological study on 272 people born with atypical sex characteristics found exceptionally high rates of early school leaving and high rates of poverty (see, for example, T. Jones 2016).

Schneuer and colleagues have also published on long term outcomes in male-assigned genital anomalies. NSW population data comparing “420 boys with hypospadias, 873 with UDT [undescended testicles], and 77,176 unaffected boys” found “no increased risk of poor early childhood development across physical, cognitive, social and emotional domains among boys diagnosed with hypospadias or UDT” but that “boys with UDT and coexisting congenital anomalies were more likely to have poorer developmental outcomes and have special needs associated with physical or intellectual disability” (Schneuer et al. 2017). This study does not appear to have assessed early exposure to general anaesthesia in either population cohort.

6.2.5 Clinical studies with relevance to clinical decision-making and beliefs

O’Connor, Harris and Buchbinder have studied unnecessary surgical procedures. They comment

Doctors tend to overestimate how good their treatments are and underestimate the harms that come from them. Surgeons are often faced with patients in pain and, other than surgery, have little else to offer except continued non-operative treatment, reassurance and time (O’Connor, Harris, and Buchbinder 2018).

Indeed, a systematic review of benefits and harms of treatments published in 2017 found that:

Clinicians rarely had accurate expectations of benefits or harms, with inaccuracies in both directions. However, clinicians more often underestimated rather than overestimated harms and overestimated rather than underestimated benefits. Inaccurate perceptions about the benefits and harms of interventions are likely to result in suboptimal clinical management choices (Hoffmann and Mar 2017).

The 2013 Senate inquiry and multiple several studies demonstrate the subjective nature of assessments of “normality” in genitals:

3.100 What little research exists regarding 'adequate' or 'normal' genitals, particularly for women, raises some disturbing questions. A British team of Jillian

Lloyd and others measured variations in the dimensions of female genitalia in a small group of 50 women aged between 18 and 50 who did not have any medical condition affecting their genitals. Even in this very small sample, there was enormous variation in the size of genitalia, with the largest clitorises 700 per cent longer, and over 300 per cent wider, than the smallest; the largest labia minora 500 per cent longer, and 700 per cent wider, than the smallest; and with the longest vagina twice the length of the shortest. Despite this range, a recent reference work on surgery on intersex patients in infancy refers simply to creating 'a clitoris that is in the right position and of the right size', without any elaboration, or discussion of what that size might be. 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.

3.101 Studies such as that by Lloyd and others indicate that there is enormous natural variation in the anatomy of sex. However, this is not necessarily reflected in the medical response to that variety. A group of Dutch researchers surveyed 164 physicians regarding their views about the desirable size of a woman's labia minora, by assessing their 'willingness to refer for, or perform, a labia minora reduction'. The doctors were divided into three groups: plastic surgeons, general practitioners, and gynaecologists, and shown pictures of female genitalia with different sized labia. The researchers found that all the doctors regarded smaller labia minora as ideal, and male doctors were more likely to recommend surgery than female, regardless of specialisation. (Community Affairs References Committee, Senate of Australia 2013).

The Dutch study is by Reitsma *et al*, who conducted a multi-centre study of 210 physicians in the Netherlands in 2009. The study examined the dispositions of general practitioners, gynaecologists and plastic surgeons to refer or perform a surgical labia minora reduction. 164 physicians completed the survey, carried out with a “five-point Likert scale appraisal of four pictures showing a vulva, each displaying different sizes of labia minora”:

*Questions were posed concerning physicians' personal predisposition to the vulvas, with regard to naturalness, attractiveness (i.e., the extent of appealing), the physician's private ideal (i.e., the overall preference), and what the physician believed to be society's ideal. Skin color, pubic hair growth, potential irregularities, and asymmetries were comparable among the pictures, thereby eliminating potential biases... Almost all of the participating plastic surgeons (90.7%; 39/43) and the majority of the gynecologists (58.5%; 24/41) had performed a labia minora reduction procedure in their clinical practice (Reitsma *et al*. 2011)*

The survey results indicated:

- *Ninety percent of all physicians believe, to a certain extent, that a vulva with very small labia minora represents society's ideal (2-5 on the Likert scale).*
- *More plastic surgeons regarded the picture with the largest labia minora as distasteful and unnatural, compared with general practitioners and gynecologists.*
- *Irrespective of the woman's labia minora size and the absence of physical complaints, plastic surgeons were significantly more open to performing a labia minora reduction procedure than gynecologists.*
- *Male physicians were more inclined to opt for a surgical reduction procedure than their female colleagues (Reitsma et al. 2011).*

The study found that:

the opinions of general practitioners and gynecologists, on the one hand, and those of plastic surgeons, on the other hand, diverge when considering what constitutes a natural- looking and attractive vulva. Moreover, this survey clearly reveals that gender of the physician is a significant influence: male physicians in all specialties are more inclined to perform the surgical procedure, compared with their female colleagues (Reitsma et al. 2011).

In our view, the study reveals a gendered bias on the part of practitioners, a professional bias, and the absence of standard objective measures for cosmetic perceptions of “normal” female genitals. It is clear that purportedly objective clinical evaluations are deeply enculturated and embedded in tacit stereotypical assumptions about what constitutes a ‘normal’ body. This is another example of the encapsulation of medical/clinical issues within social/cultural considerations referred to above.

6.2.6 LGBTI studies

Few “LGBTI” studies have had meaningful response rates from people born with intersex variations. IHRA has commented in detail on this issue (Intersex Human Rights Australia 2012). Such studies frequently lack relevance to an intersex population, and in particular a non-LGBT intersex population. Such studies may be framed around identities, with limited relevance to an intersex population; such frameworks may also exacerbate misconceptions about intersex people. Such studies may assume agency in consenting to medical interventions, and presume particular identities, experiences or behaviours. For example, by assuming that intersex people are, as a population, necessarily non-heterosexual, or non-cisgender.

These issues are also the case with many LGBTI educational and information resources. Such resources typically assume that LGBTI people are old enough to have agency to express an identity. Intersex women and men can be othered as having non-binary gender identities (Androgen Insensitivity Syndrome Support Group Australia et al. 2017; Intersex Human Rights Australia 2018a; Carpenter 2018a).

6.2.7 Legal case studies

Numerous articles have commented on Family Court cases, dating back to at least 1980 (Kennedy 2016; Finlay 1980; Bailey 1979). Multiple articles have expressed profound concerns with the decision and evidence put to the Family Court in the case *Re: Carla*, in 2016. These provide valuable insights for this consultation, and we refer to them in this report (Carpenter 2018a, 2018c; M. Jones 2017; Kelly and Smith 2017; O’Dwyer 2017; Richards and Pope 2017).

6.2.8 Community-based research

Concerns with clinical practices have been raised by Australian advocates over two decades. 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.

What about the 8% of children with intersex conditions who are raised in the wrong sex? Are these children’s lives not worth the price of waiting to perform irreversible surgery? (Briffa 2004)

Research by Morgan Carpenter discusses the Family Court cases *Re: Carla*, *Re: Kaitlin*, and also presents some statistical analysis on numbers of relevant Medicare procedures. IHRA has raised concerns that clinical research may have different priorities to community-based participatory research (Carpenter 2018a).

We strongly favour community-based research, and provision by intersex community organisations of information and educational resources. At present, these are held back by limited access to financial resources.

6.2.9 Sociological research

Some research has been published from a 2015 study of 272 people born with atypical sex characteristics (T. Jones 2015, 2016, 2017). Members of IHRA and AISSGA were part of the reference group, and clinical bodies were invited to help distribute the study’s survey. The scale of this study exceeds the scale of any other study in Australia and, indeed, most studies internationally.

In sociological research on doctors’ beliefs, Georgiann Davis observes that clinicians have essentialist beliefs about sex and gender, such that doctors believe that sex characteristics, gender and sexuality should correlate:

Dr. C. shared that the team “need[s] to figure out hormonally if the child makes testosterone. We need to figure out genetically what the chromosomes are and then discuss what little knowledge we have in 2010, how we think this child’s going to think. Not in terms of gender preference or who they’re attracted to of

course, but for gender identification, who they think they are.” We can then once again see the congruence theory at play which maintains that one’s sex is neatly correlated with gender and sexuality (Davis 2011).

It is our view that research involving people born with variations in sex characteristics must be community-based and participatory, reflecting community priorities.

7 Consent

7.1 Question 5: Seeking consent

“How is the consent of a person born with a variation in sex characteristics currently sought prior to a medical intervention?”

The Family Court case *Re: Marion* established a principle that, to be simplistic, parents can consent to most medical interventions on their children, with the exception of those deemed non-therapeutic.⁴ The term therapeutic is not well defined. In the case *Re: Carla*, Forrest J cited *Re: Marion* at [269] stating:

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

Forrest J heard that all medical witnesses found Carla’s sterilisation to be in her best interests,[32] and argued that this was in within “the bounds of permissible parental authority” [52], stating:

having regard to the cosmetic deformity, pathological condition or psychiatric disorder for which the treatment is administered and of treatment which is administered chiefly for other purposes [51] (Carpenter 2017a)

In particular, the judge determined that “it will be less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure” [30] and “the protection of Carla’s health does not “urgently” require the procedure to be carried out at

⁴ The factors which the Court considered significant in determining which cases fall outside the scope of parental authority in *Marion’s Case* were that the procedure was non-therapeutic; invasive and irreversible; that there was a significant risk of making the wrong decision; and that the consequences of a wrong decision would be grave and serious. (*Re: Marion* [250]). While subsequent cases on the scope of the special medical jurisdiction has been debated within cases such as *Re Jamie* and *Re Kelvin*, it is clear that therapeutic status of a procedure remains a key criterion, if not necessarily conclusive of the issue.

this very point in her minority ... to ameliorate real and not insubstantial risks to Carla's physical and emotional health" [51].

Numerous legal experts, bioethics and human rights experts have expressed concern with these outcomes of the case (Carpenter 2018a; M. Jones 2017; Kelly and Smith 2017; O'Dwyer 2017; Richards and Pope 2017). However, it is also clear that the prior labioplasty and clitoral surgery performed on Carla was conducted without referral to the Family Court, so it appears that this was regarded by Carla's multidisciplinary team as therapeutic.

7.1.1 The legal framework of the special medical jurisdiction of the Family Court

Subsequent to the decision in Marion's case, the Family Court has exercised its jurisdiction to make medical decisions for children where the proposed procedure lies outside the scope of parental authority. The *Family Law Act 1975* (Cth) s 67ZC confers statutory authority on the Court to make orders relating to the welfare of children and directs that in making such orders "a court must regard the best interests of the child as the paramount consideration" (Australia 2018)

The legislative framework for giving effect to best interests as the paramount consideration is set out in Part VII, Division 1, Subdivision BA – Best Interests of the Child. The objects of Part VII are outlined in s60B, and include the object of giving effect to the Convention on the Rights of the Child. Section 60CC outlines matters which a court must take into account in determining best interests. Two factors are identified as primary considerations: the benefit to the child of having a meaningful relationship with his or her parents [ss 60CC (2)(a)] and the need to protect the child from any harmful effects of abuse, neglect or family violence [ss 60CC (2)(b)]. Additional considerations are outlined in s 60CC (3). These include ensuring meaningful involvement of children in decision making (a principle referenced in the Issue Paper).

7.1.2 Best interests

The Senate committee report in 2013 provided guidance on implementing a human rights-affirming framework for medical interventions on children born with variations in sex characteristics:

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. (Community Affairs References Committee, Senate of Australia 2013)

However, the best interests test has been utilised to justify early and unnecessary medical interventions. In relation to *Re: Carla*, Kelly and Smith report

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

The judge also determined that sterilisation was in the child's best interests for avoidance of risk of cancer. Kelly and Smith comment:

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

They comment that, contrarily, in Family Court decisions regarding puberty blockers for transgender children, courts have determined that

at the time that hormone blockers are requested (typically 3–5 years before gender affirming hormones might be administered), it is not possible or appropriate to determine whether gender affirming hormone treatment will be in the child's best interests (Kelly and Smith 2017)

It appears to this extent that the best interests of intersex children, and of transgender children, have not been treated in a commensurate manner. Kelly and Smith argue that the treatment in *Re: Carla* "sets a dangerous precedent":

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

We fear that information provided to support parental decision-making may be similarly incomplete.

Kirsten Sandberg comments that psychosocial rationales have long been a rationale for regarding surgery on infants as in a child's best interests. However, she states that parents' "interest in having a "normal" child may influence what they think is in their child's best interests" and physicians are similarly unable to "make a well-informed and impartial consideration of" the child's best interests":

it is questionable if anybody else than the child itself is able to make an informed assessment of its best interests in this respect, both regarding the decision of whether or not to assign a sex, and not least, regarding what that sex should be. Consequently, even if one were to accept the assumption that the decision should be based on the best interests of the child, the decision would have to be postponed ... [and] the best interests of the child cannot override other rights under the CRC (K. Sandberg 2018).

However, the difficulty is that the *Family Law Act* provides the relevant Australian legal framework, and Human Rights conventions and treaties have no formal status in law in Australia. This means that, although the treaties can be referred to in certain circumstances in interpreting legislation, the explicit words of a statute cannot be overridden by reference to human rights articles.

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

[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; (Yogyakarta Principles 2017)

However, determinations of children's best interests in relation to medical interventions on intersex bodies do not meet these principles. *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 *Yogyakarta 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 (Committee on the Rights of the Child 2013).

The 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 (Committee on the Rights of the Child 2011).

The difficulty is that the *Family Law Act 1975* (Cth) provides the legal principles that must be applied, and explicitly gives paramountcy to best interests. This means that insights in General Comment 14 can inform the interpretation of best interests, particular given the object outline in s 60AB (4).

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 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... (Committee on Civil and Political Rights 2014)*

In our view, the 'best interests' test has been misapplied in the Family Court and in clinical decision-making processes. State obligations in the *Yogyakarta Principles plus 10* Principle 32 address this issue, restricting the scope of situations where the best interests test applies and seeking to eliminate manipulation of the concept:

- D) Bearing in mind the child's right to life, non-discrimination, the best interests of the child, and respect for the child's views, ensure that children are fully consulted and informed regarding any modifications to their sex characteristics necessary to avoid or remedy proven, serious physical harm, and ensure that any such modifications are consented to by the child concerned in a manner consistent with the child's evolving capacity;*
- E) Ensure that the concept of the best interest of the child is not manipulated to justify practices that conflict with the child's right to bodily integrity; (Yogyakarta Principles 2017)*

7.2 Question 6: Guidelines and protocols on consent

"How do current guidelines or protocols relating to the medical management of people born with variations in sex characteristics deal with the issue of consent, including the ability to withdraw any consent given at any time?"

Current guidelines and protocols regard medical interventions (other than sterilisations in a diminishing number of cases) as a matter for parents to determine. The case *Re: Carla*

expanded the range of cases where parents can make decisions on sterilisation. The case *Re: Kelvin* took decision-making on hormone interventions with parental consent out of Family court jurisdiction.

7.2.1 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’ (World Health Organization et al. 2008). 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.

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 (World Health Organization et al. 2008). Personal consent is not recognised as a justification for female genital mutilation. The World Health Organization and other bodies recognize that medicalization, including as a form of harm reduction, does not justify female genital mutilation.

Every Australian state and territory jurisdiction prohibits female genital mutilation.⁵ Despite this prohibition of female genital mutilation, labioplasties and other vulvoplasties, including for aesthetic purposes, are permitted (Kennedy 2009; Spriggs 2016; Spriggs and Gillam 2016; Shahvisi and Earp 2018). 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 (Department of Health 2014).

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.

Exemptions in Australian model laws dealing with female genital mutilation reflect profound confusion, as they appear to describe infants with “ambivalent” sex (i.e. variations of sex characteristics)⁶ 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” (Attorney General’s Department 2013). This policy framework does not discuss issues of

⁵ *Crimes Act 1900* (NSW) s 45; *Crimes Act 1958* (Vic) ss32-34A; *Criminal Code Act 1899* (Qld) s323A; *Criminal Code Act 1924* (Tas) s178A; *Criminal Law Consolidation Act 1935* (SA) s 33A; *Crimes Act 1900* (ACT) s 74; *Criminal Code Act* (NT) 186B; *Criminal Code Act Compilation Act 1913* (WA) s 306

⁶ Note that the Model Code and legislation does not refer to intersex, or DSD, but “a person whose sex is ambivalent”.

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 social belonging, parental distress and cosmetic issues (such as appearance enhancement, marriageability) mirror the rationales evident for female genital mutilation in societies where the practice is the norm (World Health Organization et al. 2008).

7.2.2 Queensland law restricting cosmetic surgery on children

Queensland legislation protecting children from cosmetic surgery with no therapeutic purpose is predicated on the concept of the child's 'best interests'. The Explanatory Notes state:

The new section 213B may be seen to override parental rights. Under this section, a cosmetic procedure cannot be performed on a child unless it is determined that it is in the best interests of the child. The determination of this resides with the person performing, or offering to perform, a cosmetic procedure, rather than with the child or the child's parents. The intent of the Bill is to prohibit such procedures except where the person performing the procedure has a reasonable belief that it is in the best interests of the child. It is therefore inappropriate to allow a child to undergo a procedure, irrespective of parental consent, unless it is in the best interests of the child for the procedure to be performed. However, when considering what is in the best interests of a child, where practicable, the views of the parent, including whether the parent supports the procedure being performed on their child, must be taken into account. It is considered that in these circumstances, the best interests of the child override fundamental legislative principles in regard to the rights of individuals (in this case, those of the parents). (Parliament of Queensland 2008).

When juxtaposed against the Family Court's assessment of genital surgeries in *Re: Carla*, that a labioplasty and clitoral surgeries "enhanced the appearance of her female genitalia", this legislation cannot be said to be effective in protecting the rights of children born with variations sex characteristics in the context of medical interventions.

7.2.3 Senate committee recommendations

The cross-party Senate report on involuntary or coerced sterilisation of intersex people called 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 (Community Affairs References Committee, Senate of Australia 2013)

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) (Community Affairs References Committee, Senate of Australia 2013)*

7.3 Question 7: Safeguards

“What practices/safeguards are in place to ensure any consent obtained remains informed?”

There are no such safeguards. Kelly and Smith identify concerns with information provision to the Courts (Kelly and Smith 2017). Parents may be told skewed and partial information about their child in ways that have a direct impact on the medical interventions experienced by their child.

However, in a commentary on evidence-based medicine, Trish Greenhalgh states “that facts are not self-interpreting: they are theory- and value-laden” (Greenhalgh 2018). Streuli and others have identified such concerns with concept and values in information disclosure:

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 (Streuli et al. 2013)

While affirmative explanations of intersex exist solely outside clinical contexts, and while clinicians interpret the viewpoints of intersex-led organisations and human rights institutions, such perspectives will be filtered through what are (at best) often limited, partial or essentialist clinical understandings of those viewpoints, and (at worst) subjected to denial.

Furthermore, silence, secrecy and a (variably persistent) legacy of concealment of diagnostic information 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” (Houk et al. 2006).

Clinicians and parents may make decisions based upon delivery room distress (Department of Health and Human Services 2015a), 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 (Greenberg 2012).

In a clinical study of parents of intersex children entitled “Medical Treatment of Intersex: Parental Perspectives”, 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’ (Dayner, Lee, and Houk 2004). However, Human Rights Watch and interACT identify in a study that clinicians are themselves unclear about who instigates decisions for surgeries:

Of the practitioners Human Rights Watch interviewed, there was considerable disagreement about whether it is doctors or parents who drive the decision about surgery.

This study found that doctors failed to make distinctions “between the kinds of decisions parents routinely make for their children, and decisions about a controversial surgery that has irreversible lifelong consequences” (Human Rights Watch 2017, 124–25).

In 1993, the same year as the establishment of ISNA (the first advocacy organisation on intersex issues) physicians discussed how they “educate” parents (Hendricks 1993), and in 2016, Mike O’Connor at Western Sydney University reported that:

Parents are often unaware of their daughters’ clitoromegaly until paediatricians point this out to them (2016).

Liao and others report that “parental regret can be high”, and parents “may not realise that they are de facto opting for experimental surgery on their children” (L.-M. Liao, Wood, and Creighton 2015), and clinicians have provided no credible non-surgical treatment pathways (L.-M. Liao, Wood, and Creighton 2015; S. Creighton 2016). In 2016, a co-author of that editorial stated in a clinical conference abstract:

Credible non-surgical pathways with ongoing psychological support for the family currently do not exist. (S. Creighton 2016)

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. (Lee et al. 2016)

This also means that there is no evidence for a position that waiting for an individual to be able to consent before performing irreversible, deferrable medical interventions is harmful.

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 (Zillén, Garland, and Slokenberga 2017)

The report of the Committee on Bioethics found that:

- *surgery ... in infancy [is done] on the assumption that parental rearing could steer gender development.*
- *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 (Zillén, Garland, and Slokenberga 2017)*

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 (Zillén, Garland, and Slokenberga 2017)

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.

7.3.1 Experimental treatments

The 2017 Committee on Bioethics of the Council of Europe 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 (Zillén, Garland, and Slokenberga 2017)

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 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” (K. Sandberg 2015).

Yogyakarta Principle plus 10 Principle 37 on the Right to Truth 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 (Yogyakarta Principles 2017).

7.4 Question 8: Enhancing capacity for consent

“What could enhance the capacity of people born with variations in sex characteristics or their caregivers to provide full and informed consent?”

Unless required for urgent or strictly-interpreted medical necessity, that is, essential for physical health, medical interventions should be deferred until individuals can personally provide informed consent.

Parents, carers and individuals need access to independent, resourced, affirmative peer support, and organisations providing systemic and individual advocacy.

Intersex-led peer and advocacy organisations should be funded to develop information and staffing resources to support decision-making. These should include guides to the provision of information to parents and individuals within clinical settings.

8 Consent in the absence of legal capacity

8.1 Question 9: Parental decision-making

“To what extent should parents and carers be involved in making decisions on behalf of their child? How can parents and carers be best supported to make these decisions?”

A 2016 clinical update to the 2006 clinical “consensus statement” suggests that:

community members now call for evidence-based interventions, the consistent inclusion of evidence and of controversies in informed consent processes and the creative identification of alternative strategies, including psychosocial support and [peer support] as primary interventions (Lee et al. 2016)

We agree that parents need support to adapt, accept and affirm their child. Access to affirmative peer support is an essential component in this process. However, certain interventions are not acceptable *with or without parental consent*, and disclosure of controversies, wherever or however this may occur, is insufficient. Kirsten Sandberg comments:

if an intervention is performed with parental consent at an earlier stage without being strictly medically necessary for vital bodily functions, or going further than needed, this is a violation of the child’s right to identity under art. 8 and the right to integrity under art. 19, and will be contrary to the best interests of the child under article 3.

Under article 18 (1) CRC parents have the primary responsibility for the upbringing and development of their children, including for making decisions on behalf of the child. However, their competence is limited by the child’s right to identity, integrity and participation. A further limitation follows from the same provision, stating that the best interests of the child “will be their basic concern”. Consequently, where a treatment can be postponed until the child can at least form a well-reasoned view or even decide for itself, the parents cannot validly consent to such treatment (K. Sandberg 2018).

Parents are already entitled to make many medical decisions on behalf of their children, but not others. Some decisions should not be put to parents by clinicians for them to consider. Parents should not be confronted by requests from clinicians that they consent to irreversible, deferrable modifications to the sex characteristics of people born with variations of sex characteristics. Nor should parental requests for such interventions be fulfilled.

Parents need support to enable decision-making, and to understand and care for their children. Access to affirmative peer support, systemic advocates, and psychological support is essential and must be facilitated.

8.2 Question 10: Oversight

“What, if any, legal oversight mechanism(s) should be in place to guide decision-making about medical interventions involving a person born with a variation in sex characteristics where the person does not have the legal capacity to provide consent?”

8.2.1 Multi-disciplinary teams

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 (Community Affairs References Committee, Senate of Australia 2013). This means that assurances of change to clinical practices in one hospital should not be taken to imply national consistency. 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 (Reitsma et al. 2011; Davis 2011, 2015). Morgan Carpenter comments:

Reviewing the evidence from both public and private submissions, Senators in that inquiry reported that ‘there is no medical consensus around the conduct of normalising surgery’. Indeed, this statement is reflected in literature and personal communications with clinicians who are able to make claims about their work and that of their own teams, but who otherwise acknowledge great variation in practices within hospitals, between hospitals, and between jurisdictions, often determined by the beliefs of the clinician with whom parents have first contact...

While the 2006 ‘Consensus Statement’ promoted the concept of multidisciplinary teams, Sarah Creighton has pointed out that their existence is no guarantee of changed clinical practices when they may be led by, and for, surgeons committed to early intervention and no credible non-surgical pathways yet exist. Psychological support for families and individuals remains marginalised with patchy availability. (Carpenter 2018a)

Georgiann Davis comments:

Medical authority over intersex conditions was also reasserted by advocating for and implementing medical management “teams” that would consist of various “experts” on intersex conditions... In the face of challenged medical authority, medical professionals are able to reclaim and reassert their positions as experts by operating in teams. At the same time, they are able to minimize any potential liability for hormonally and/or surgically treating intersexuality...

While DSD medical management teams are allegedly now operating in teams with expertise from across professions, those from psychiatry are typically less involved. Their exclusion makes sense because psychiatrists are less likely than surgeons to hold essentialist beliefs about sex, gender, and sexuality. Instead, psychiatrists are likely to see intersexuality as a social phenomenon, “or at the very least, a shared medical-cultural phenomenon” (Davis 2011)

The Human Rights Watch/interACT report found similar issues:

One of the main problems within DSD teams, some practitioners told Human Rights Watch, was the divergent views from different disciplines of medicine, and the power structures that privileged surgeons’ opinions and advice to parents. While DSD team members interviewed repeatedly cited psychosocial reasons for performing genital surgeries on infants, and reported that mental health services were made available to parents as part of their decision-making process, some mental health providers emphasized that their input was rarely valued or utilized (2017).

The Family Court judge in the case *Re: Carla* heard from three members of the multi-disciplinary team for the child. while we agree that children should be seen by staff working within a multi-disciplinary team, to ensure that any necessary treatment meets minimum technical standards, such teams do not intrinsically protect the human rights of the child. Indeed, 2006 guidelines by the Accord Alliance, recommending multidisciplinary teams, stated:

*Although dedicated multidisciplinary teams which focus on patients’ psychosocial well-being may be more likely than alternatives to provide optimal care, **a dedicated multidisciplinary team is neither a guarantor of nor a necessity of patient-centered care for DSDs** (Consortium on the Management of Disorders of Sex Development et al. 2006).*

The Human Rights Watch/interACT report states:

the establishment of DSD teams, while a positive development in that it has decentralized decision making, has not addressed the roots of the problem—that parents are not getting full information and unbiased advice about surgical procedures, and that medically unnecessary surgical procedures that carry significant risk of harm continue to be presented as legitimate options (2017).

Faced with a paediatric urologist in a multidisciplinary team meeting, parents Eric and Stephani Lohman have described how they were offered two choices, both involving surgery when their child was aged six months (Lohman, Lohman, and Davis 2018, 87–88). When questioned by the Lohmans on the lack of a non-surgical alternative, the surgeon “would not recommend that option”:

Other participants in the team meeting “were avoiding eye contact ... It seemed that the design of the DSD team had a limitation, whereby if no one is willing to

challenge the surgeon in the room, then the team is merely there to serve him or her with an audience. (Lohman, Lohman, and Davis 2018, 88–89)

Multidisciplinary teams must operate within a framework that respects and affirms children’s human rights, as described in statements by UN Treaty Bodies and the Office of the High Commissioner for Human Rights (Human Rights Committee 2017; Committee on the Elimination of Discrimination against Women 2018; Office of the High Commissioner for Human Rights et al. 2016; K. Sandberg 2018, 2015).

8.2.2 Family Court oversight

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:

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. (Bryant 2013)

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 appear 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*, 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” (Kennedy 2016).

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. (Kerridge, Lowe, and Stewart 2013).

They also argue that the distinction appears to have been ineffective “in stopping the number of non-approved sterilisations” of children with disabilities (Kerridge, Lowe, and Stewart 2013). This is unsurprising when the Family Court has been willing to grant parental authority to consent to sterilisations of children. The authors also state that the Court process is expensive and cumbersome.

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 cases approving medical procedures performed on intersex children are characterised by a consensus among the parties that the proposed procedures are in the child’s best interests. In each of the 8 cases concerning intersex children which have been heard by the court, the respondent explicitly supported the application, meaning that there was no testing of or challenge to the application or evidence supporting it. In each case, either the hospital, health authority, mother, father or some combination acted as applicant and respondent. In this sense each of the respondents is a respondent in ‘name only’ (*Re Sarah* [16]). While the Family Court Act 1975 (Cth) s 68L explicitly provides for children and minors to be represented by an independent Children’s Lawyer, an ICL has been appointed in only one of the eight cases concerning intersex children, *Re Sarah*. This is surprising given that Sarah was 17 years old at the time of the hearing, and was found to be Gillick competent. By contrast, in the cases *Re Lesley*, *Re Carla* and *Re Sean and Russell*, concerning very young children, no independent children’s lawyer was appointed. In *Re Sean and Russell*, Murphy J provided a lengthy explanation for his decision which focussed on the consensus and lack of dispute regarding the proposed procedure. Similar reasons were relied on in *Re Lesley*. The possibility was not adverted to in *Re Carla*. Justice Barry in *Re: Lesley* commented:

48. In reaching the conclusion I am only too conscious of anecdotal accounts of individuals having gender reassignment procedures later in life, having great difficulty accepting the situation that has been thrust on them. On the medical evidence available that would not be indicated as likely in Lesley's case. I note that many of the accounts are sensationalised in the media. I far prefer the evidence set out in the medical reports (Family Court of Australia 2009).

In other words, Justice Barry actually stated that he is aware of dissenting voices among those with lived experience, but he chose to discount it. His reasons for ignoring the dissent were firstly that dissatisfaction later in life is not likely in Lesley's case. He said this despite the sections of his judgment in which he refers explicitly to the evidence that the majority of children with Lesley's variation identify as male at puberty. Secondly, he argued that the media sensationalises these accounts. But rather than trying to get to the bottom of the media reports, he rejected them without further inquiry or exploration. Finally, he

commented that he prefers the medical evidence. this is a stark example of dissenting voices being ignored.

In five intersex cases put before the Family Court, an intervenor or amicus was appointed by the court, usually the relevant state child welfare department. However, none of the intervenors or amici curiae opposed the application, sought to adduce other evidence, challenged any medical evidence or cross examined any of the medical witnesses. In other words, a commonality among all of the cases concerning intersex children is the lack of any challenge to the medical evidence, any testing of the evidence via cross-examination or any attempt to adduce contradictory evidence. This is concerning in many of the cases, where the medical evidence does not represent a consensus within the medical community and the clinical literature. Concerns expressed over decades by intersex adults and organisations, by dissenting clinical voices, and by human rights institutions have wrongly been disregarded. The lack of effective contradictor in every one of these cases has meant that contestable and selective evidence has gone unchallenged. This represents a significant deficiency in the ability of the Family Court to provide appropriate oversight and monitoring.

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.

8.2.3 Independent oversight

In line with the *Darlington Statement* and the *Yogyakarta Principles plus 10*, we believe that any non-deferrable interventions which alter the sex characteristics of infants and children undertaken before their ability to consent on their own behalf should be identified as notifiable medical treatment outside the scope of parental consent and requiring oversight from an independent body. Deferrable interventions should be prohibited. The oversight body should be tasked with, where appropriate, determining whether or not medical interventions are necessary and non-deferrable. In relation to adults with disabilities born with variations in sex characteristics, provision must be made to facilitate supported decision-making on an equal basis with other adults. Resourced intersex peer and systemic/individual advocacy organisations should be resourced to assist in these matters.

To ensure adherence and transparency with these provisions, the independent oversight body must be notified, post facto (after the event), of details of all cases involving either minors or adults with supported decision-making where informed consent and/or urgent non-deferrable medical necessity have been asserted.

8.3 Question 11: Oversight operation

“If such a mechanism existed: how could this mechanism adequately address different interventions and different variations? how can it best respect the future capacity of a child to consent? should there be distinct processes for children with parents and for adults who lack legal capacity?”

In line with the *Darlington Statement*, intersex human rights defenders call for effective oversight of medical interventions on children born with variations of sex characteristics. While we call for lines between therapeutic and non-therapeutic interventions to be redrawn in a more appropriate place, between deferrable and non-deferrable irreversible interventions, this is due to recognition that distinctions between therapeutic and non-therapeutic interventions may remain unclear in some cases.

We call for oversight via a new independent body, underpinned and embedded within a human rights framework, with meaningful participation by human rights experts, clinicians, and intersex-led community organisations. It must not operate within a welfare framework. An oversight body should be led by a human rights expert with meaningful and effective participation by intersex-led community organisations including IHRA and AISSGA and disability representative organisations. The body must include clinical representatives with diverse perspectives, including mental health perspectives and perspectives gained from work with adults as well as children.

In considering non-deferrable medical necessity in cases of doubt, the pros and cons of medical treatment must be properly ventilated and considered, including the lifelong health, legal, ethical, sexual and human rights implications. Determination that treatment is non-deferrable and medically necessary must be premised on provision of all available medical evidence on necessity, timing, procedure, and evaluation of outcome of medical interventions. The state is obligated to provide all supports necessary for children and adults to give free and informed consent to medical intervention within Article 12 of the *Convention on the Rights of Persons with Disabilities* and General Comment 1 (Committee on the Rights of Persons with Disabilities 2014).

Where there is no clinical consensus, this must be disclosed. Such a body must not be a substitute for consideration of human rights norms that have been articulated by UN Treaty Bodies and other institutions. Where treatment violates the rights of the child, it must not take place. The primary purpose of an oversight mechanism is to ensure that the human rights of individuals subjected to medical interventions are respected. A model developed for the protection of people born with variations of sex characteristics may serve as a test case or model for the benefit of other populations, including children with intellectual and/or psychosocial disabilities, and others that are often subjected to “special medical procedures”.

A grey zone exists between intersex variations and endosex (non-intersex) variation; between diagnoses defined at any time as “disorders of sex development” and those defined using other terms; and between variations of sex characteristics and other sex characteristics. The design of an oversight body should consider the implications of a situation where terms may be gamed, and where explicit rationales change over time while practices and procedures remain unchanged. To eliminate the possibility of gaming, and to ensure adherence and transparency, the independent oversight body must be notified, post facto (after the event), of details of all cases involving either minors or adults with supported decision-making where informed consent and/or urgent non-deferrable medical necessity have been asserted. Resourcing must be commensurate with this task.

Oversight is one component in a broader strategy that must also include:

- A legal prohibition of deferrable medical interventions on people born with variations of sex characteristics
- The development of human rights-affirming standards of care or guidelines
- Public and clinical education

We address these companion issues below.

9 Medical necessity

9.1 Question 12: Defining medical necessity

“Would a legal definition of medical necessity or therapeutic treatment be helpful and, if so, what should the definition be?”

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. As observed in the *Darlington Statement*, 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 (Androgen Insensitivity Syndrome Support Group Australia et al. 2017). This criterion should be abandoned as a threshold test of whether a medical procedure requires oversight or authorisation from a decision-making forum.

UN Committee on the Rights of the Child member and former chair Kirsten Sandberg comments that the concept should be interpreted narrowly in terms of bodily functions, but also that medical issues should not be seen in isolation:

In light of the far-reaching consequences for the child, it should be interpreted strictly and probably limited to cases where the child’s vital bodily functions otherwise would not work. Even then the intervention should be limited and carried out without assigning a sex unless it is an unavoidable part of the process. (K. Sandberg 2018)

Yogyakarta Principles plus 10 Principle 32 states:

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.

State obligations in Principle 32 further comment in line with General Comment 14 ‘on the right of the child to have his or her best interests taken as a primary consideration’ by the UN Committee on the Rights of the Child (2013):

D) Bearing in mind the child’s right to life, non-discrimination, the best interests of the child, and respect for the child’s views, ensure that children are fully

consulted and informed regarding any modifications to their sex characteristics necessary to avoid or remedy proven, serious physical harm, and ensure that any such modifications are consented to by the child concerned in a manner consistent with the child's evolving capacity;

E) Ensure that the concept of the best interest of the child is not manipulated to justify practices that conflict with the child's right to bodily integrity; (Yogyakarta Principles 2017)

It is our view that a definition of medical necessity is necessary, and must be drawn tightly, while permitting emergency and urgent interventions.

Timing is relevant to the concept of medical necessity. Unduly early procedures may pre-empt alternative procedures, the choice of not undergoing treatment, as well as the right of an individual to consent to treatment. It is for these reasons that the *Darlington Statement* refers to the concept of a “deferrable” medical intervention.

A concept of medical necessity must also take account of timing. A procedure which may be necessary at some point in the future of an infant or child should be undertaken at that future point and not before it becomes necessary.

It is our view that an appropriate definition of medical necessity is, unfortunately, insufficient. The following are prerequisites for any definition of medical necessity to have the desired effect:

- Penalties for noncompliance, such as criminal penalties
- Oversight of all relevant decisions, for example, post facto (after the fact) oversight of medical interventions where medical necessity or personal informed consent are asserted.

9.2 Question 13: Permissible rationales and considerations

“What are the permissible rationales/considerations that should be taken into account when determining whether or not to undertake a medical intervention on behalf of those who lack the capacity to consent?”

Medical interventions must not be approved 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). Surgeries may also take place in the belief that they “resolve” long term issues without a need for peer and other psychological support; peer and other psychological support is not satisfactorily resourced.

We note that clinically favoured rationales have changed over time, but less than might be expected, even while there are (unsubstantiated) claims of changing practices over that time. For example, Kuhne and Krahl identify as key rationales in 2002:

The question asked is not so much what the individual is, but which gender is a better fit. The major criteria influencing decisions on sex assignment are functionality, future pubertal development, and fertility. Consequently, genetic male patients with phallic structures considered to be too small are raised as girls; whereas severely or completely virilized females with congenital adrenal hyperplasia are also raised as girls, with the main argument in the latter case being that future female fertility may be possible (Kuhnle and Krahl 2002)

The criteria in their second sentence remain evident today.

This means that oversight is essential regardless of rationales for medical interventions, in order to eliminate the possibility that restrictions on certain rationales might be circumvented. This is also why we favour approaches grounded in the universality of human rights.

9.2.1 Psychosocial rationales

Psychosocial rationales for medical interventions are not grounded in evidence, nevertheless, they appear to be proffered as reasons for early medical interventions, and entangled with other rationales. These include claims about parental distress and bonding, and related claims about gender and psychological development, and stigmatisation if genitals do not match sex of rearing.

The 2006 “Consensus statement on management of intersex disorders” based its reasoning on early cosmetic interventions on clinical feelings and beliefs:

It is generally felt that surgery that is carried out for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents. The systematic evidence for this belief is lacking (Hughes et al. 2006, 557)

A 2016 global update to the 2006 clinical statement reported that there is no evidence to support claims that surgery affects risk of stigmatisation (Lee et al. 2016).

Nevertheless, a 2010 set of paediatric ethical principles developed in Melbourne identified as risks that could be mitigated through surgical interventions:

- *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*
- *Risk of social isolation, restrictions or difficulties, for example caused by embarrassment or social stigma associated with having genitalia which do not match the gender in which the person [child] lives (Gillam, Hewitt, and Warne 2010)*

Regarding 'Reconstructive reduction of an enlarged clitoris or repair or construction of a urinary outlet to the end of the penis', the Australasian Paediatric Endocrine Group has stated 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. (Australasian Paediatric Endocrine Group et al. 2013)

We regard these as cultural, not functional, requirements for cosmetic interventions; and the stated psychosocial rationales lack evidence of necessity. As psychosocial rationales, these claims appear to be associated with the belief that children necessarily grow up with shame about having a variation of sex characteristics, but this is in our view a function of family support and love, and affirmative access to peers.

Despite making such claims, the Australasian Paediatric Endocrine Group notes 'particular concern regarding sexual function and sensation' following these interventions (Australasian Paediatric Endocrine Group et al. 2013).

In its 2013 report responding to submissions on involuntary or coerced sterilisation, the Senate committee considered the evidence put to it, and 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 (Community Affairs References Committee, Senate of Australia 2013)

It is our view that clinicians fail to consider the impact on family decision-making of their own essentialist ideas. As a consequence, clinicians fail to consider their own role in promoting and reinforcing the social norms that comprise psychosocial rationales. These ideas and norms include the fallacious idea that a young child's physical sex characteristics need to match legal sex assignment (Davis 2011). This idea is not consistently applied, such as to prepubertal transgender children who have socially and/or legally transitioned. Unlike intersex children, pubertal transgender children may be given access to puberty blockers and, when able to consent, to irreversible hormone treatment.

Regarding rationales for surgery based on parental distress and impaired bonding, the parents of a child with CAH, Eric and Stephani Lohman state:

The major problem is that there simply are no studies that support the idea that a child's mental health is negatively impacted by having an intersex body... Moreover, suggesting that parents cannot adequately love a child whose body is different from what they imagined it would be is absurd. Parents all over the world provide unconditional love to children with a variety of special needs, many of whom are not even their biological progeny (Lohman, Lohman, and Davis 2018, 30)

Eric and Stephani Lohman also described rationales for medical intervention predicated on the avoidance of identity issues, commenting:

The position that we hold is that even if a child were to grow up with feelings that were not strictly male or female, then that would not be such a terrible outcome... The burden rests on us as a society to accept variations within our population, not with the individual to change themselves to fit an arbitrary standard (Lohman, Lohman, and Davis 2018, 111–12)

A 2017 report by the Committee on Bioethics of the Council of Europe found that, still, the associated “claim that gender development requires surgery is a ‘belief’ unsubstantiated by data” (Zillén, Garland, and Slokenberga 2017)

Kirsten Sandberg identifies the right to privacy as being engaged by medically unnecessary interventions on people born with variations in sex characteristics. She comments:

The obligation of the state is to respect the right of the child to “preserve” his or her identity. When a child is born with an intersex condition, it is part of the child's identity at that time, and preserving it would mean that it should not be changed. This is especially so since any surgical sex assignment is an irreversible process (K. Sandberg 2018)

We believe that psychosocial rationales for medical interventions are unacceptable without personal informed consent. Affirmative access to peers is strongly recommended in such cases.

9.2.2 Family culture

In multiple settings in Australia, we have heard that parent culture plays a role in determining whether or not a child undergoes surgical interventions. There is considerable evidence that parent culture impacts on sex assignment and surgical interventions. In what is regarded as a significant study, Kuhnle and Krahl published a paper on the impact of culture on sex assignment (and, therefore, surgical intervention):

There is evidence that attitudes concerning gender and sexuality, including the acceptance of intersexuality, differ significantly between various cultures...

They also comment that cultural bias is not “generally accepted”:

Observing the development of intersex patients from different cultural backgrounds made it quite obvious to us that the current medical approach to intersexuality is guided more by cultural bias than by objective medical criteria. The idea that cultural background should guide medical decisions is nowhere generally accepted—neither among our medical colleagues in Europe and the United States nor among our Asian colleagues.

However, they found significant evidence of this in practice:

While we were working with different ethnic groups [in Malaysia], it was never difficult to convince a Muslim family to assign a severely virilized girl or an undervirilized boy to the female gender. This was not the case for Chinese and Indian families, who on several occasions took off with their ambiguously born child when female sex assignment (or reassignment) was suggested (Kuhnle and Krahl 2002).

Treating children differently depending upon their parents’ culture means that different children with the same diagnosis will be treated differently. This risks being a form of discriminatory treatment. Cultural differences have been attributed to decision-making on other matters relating to sexual and gender minorities (for example, Jacobs and Abou Hamad 2017). This may also represent a stigmatisation or scapegoating of families from minority cultures, including a stigma of low expectations, and a desire not to invest in time and effort to improve communication.

We believe that cultural rationales for medical interventions are unacceptable without personal consent.

9.2.3 Medical rationales based on urgency and high cancer risks

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. Some details of a private submission to the 2013 Senate committee inquiry by Cools and others emerged in the committee’s report, to show 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. (Cools et al. 2013)

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” (Amnesty International 2017).

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 (Community Affairs References Committee, Senate of Australia 2013)

This encapsulation appears relevant to the Family Court case *Re: Carla*, where cancer risks in relation to 17-beta hydroxysteroid dehydrogenase 3 were overstated and based on obsolete clinical data, contradicting the 2006 clinical “consensus statement”. Neither the *ICD-11 Foundation* nor the 2016 global clinical update raise concerns regarding cancer risks in relation to 17-beta hydroxysteroid dehydrogenase 3 (World Health Organization 2018b; Lee et al. 2016); we discuss these issues further below in the section on technical rationales.

These factors mean that oversight is required for medical interventions predicated on concerns of urgency and medical necessity. We have no wish to reduce the timeliness of urgent or emergency medical interventions. We regard *post facto* (after the fact) oversight as appropriate in such circumstances.

We note that data on cancer risk is scarce, including where monitoring may be recommended. We have also heard claims that legal impediments may exist to prevent monitoring, even where this is recommended in clinical guidelines and “consensus statements”. This is surprising to us but, if there are such impediments, they need to be eliminated.

9.2.4 Timing

Arguments that early surgery has better outcomes lack adequate evidence and lack clinical consensus. For example, the 2016 clinical update to the 2006 “consensus statement” remarks:

There is still no consensual attitude regarding indications, timing, procedure and evaluation of outcome of DSD surgery. The levels of evidence of responses given

by the experts are low (B and C), while most are supported by team expertise (Lee et al. 2016)

Historically, attempts to generate evidence have suffered from overzealous medical interventions, disinterest, and deliberate concealment of diagnoses. Furthermore, obtaining adequate evidence requires experimentation on human subjects, or is subject to bias. Forms of bias include selection bias, and the shaping of patient responses by clinical beliefs and opinions (Carpenter 2018a, 460–61).

Arguments in favour of early intervention include the idea that individuals may suffer less, through traumatic memory or stigma and discrimination. These are psychosocial rationales.

There is no evidence to support the contention that surgery saves people from stigma and discrimination. Indeed, the Senate has identified this as a “circular” argument. If accepted in the case of children with intersex variations, why not accept it for other stigmatised children?

The idea that early interventions save children from the memory of potentially traumatic surgical experiences is evident in *Re: Carla*, where Forrest J stated:

less psychologically traumatic for Carla if it is performed before she is able to understand the nature of the procedure (Family Court of Australia 2016)

Forrest J attributed this trauma not only to the surgical memory but primarily to the psychological implications of knowing something about her body. This argument is profoundly troubling. While some of Carla’s sex characteristics may have been changed to go along with her “Minnie Mouse underwear” and “glittery sandals”, her surgical history (and its rationales) and unalterable sex characteristics such as chromosomes remain facts that require disclosure, along with information about her fertility and need for ongoing medical treatment (sterilisation requires hormone replacement therapy from puberty onwards). Consideration of the lifelong consequences also, then, helps to identify that medical intervention is not completed at the conclusion of a surgical act; medicalisation is a lifelong experience.

These arguments in favour of early medical interventions to modify sex characteristics are inadequate. Irrespective of their adequacy as arguments, they unnecessarily pre-empt children’s rights to consent to such interventions; they violate rights to (inter alia) bodily integrity, privacy, identity, and non-discrimination.

9.2.5 Technical considerations

In 1993, Melissa Hendricks reported that:

Doctors who work with children with ambiguous genitalia sometimes put it this way: ‘You can make a hole but you can’t build a pole.’ (Hendricks 1993)

This rationale was disavowed in a 2016 update to the 2006 clinical “consensus statement”. This states:

The previously widespread routine assignment of 46,XY newborns with markedly hypomaskulinized genitalia as females has given way to more detailed considerations of biological factors involved in combination with gradually increasing evidence for syndrome-specific long-term outcomes (Lee et al. 2016)

Like other claims made about changing clinical practices, this statement is weak and lacks evidence. It is not clear what is meant by “more detailed consideration of biological factors”. Statements about outcomes in 5 α -reductase deficiency and 17 β -HSD3 deficiency neglect to consider the role of surgery in producing negative outcomes; and clinical guidelines are incapable of offering definitive assessments of future gender identity and desires.

However, Morgan Carpenter links this rationale, to the World Health Organization’s *International Classification of Diseases (ICD) 11 Foundation*, and the practices detailed in the Family Court case *Re: Carla* where the child had 17 β -HSD3 deficiency.

Regarding 5 α -reductase deficiency, the global update states that:

individual male or female assignment should be based of[sic] physical development, hormonal secretion, the presence/absence of genetic mutation and the response to hormonal therapy, particularly DHT (Lee et al. 2016)

The *ICD-11 Foundation* code information states:

Gender assignment is still debated and must be carefully discussed for each patient, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy should be performed. Prenatal diagnosis is available for the kindred of affected patients if the causal mutations have been characterized (World Health Organization 2018a)

It appears that “expected results of masculinizing genitoplasty” are a proxy for what the global update describes as “physical development”. Linking the “expected results of masculinizing genitoplasty” to sex assignment is based on the idea that “You can make a hole but you can’t build a pole”. It should also be noted that “masculinizing genitoplasty” encapsulates a range of surgical interventions including “hypospadias repair”.

In relation to 17 β -HSD3 deficiency (the diagnosis of the child in *Re: Carla*), the global update states:

For those with 46,XY with 17 β -HSD3 deficiency, care must be taken to assess all aspects, since there is evidence of satisfactory sexual function both among those raised male and those raised female. Among those raised male, there is considerable penis length dissatisfaction, and among those raised female, there is clinical distress.

It is important to note that “evidence” of sexual function implies no more than some evidence of a heterosexual capacity to penetrate or be penetrated; it does not imply sexual sensation. The *ICD 11 Foundation* states:

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

Linking the results of masculinizing genitoplasty to sex assignment is here likewise based on the idea that technical considerations are critical to sex assignment.

In cases of both 5 α -reductase deficiency and 17 β -HSD3 deficiency, the concept of “expected results” of surgery is also based on the idea that children need sex characteristics that match their assigned sex. Thus, technical and psychosocial rationales are linked. Technical considerations are factors when clinical papers discuss how children “need” sex characteristics that match their assigned legal sex.

The circumstances described in *Re: Carla* fit these rationales, “markedly under virilised for a genetic male” with female assignment leading to “feminizing genitoplasty” without oversight, and subsequent gonadectomy with Court imprimatur. That case was taken to “test the significance of the Family court’s approach in the [prior case] *Re Lesley*” (Kelly and Smith 2017).

Arguments in favour of technical considerations are blunt and prescriptive. These frameworks do not permit individuals with these intersex variations to make their own choices about proposed irreversible medical interventions. They make assumptions about future identity and desires that cannot be predicted with accuracy. Irrespective of their predictive capacity they unnecessarily pre-empt children’s rights to consent to such interventions; they violate rights to (inter alia) bodily integrity, privacy, identity, and non-discrimination.

9.2.6 Financial considerations

In 2016, Sarah Creighton observed at a meeting of the European Society for Paediatric Endocrinology:

Families find adjustment to the birth of such a child challenging and genital surgery is often the only or at least the main treatment option discussed. 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. Whilst parents may prefer to defer genital surgery until their child is old enough to take part in the decision making process, they may also feel ill-

equipped to negotiate the undoubted challenges of childhood until that time. Credible non-surgical pathways with ongoing psychological support for the family currently do not exist (S. Creighton 2016)

These financially-driven rationales for surgical intervention are unacceptable. They are not based on the needs of the child, nor respect for the child's human rights. They do not meet the needs of the individual and family. Parents should never be put in the position of feeling that surgery resolves otherwise complicated psychosocial issues, and they must feel supported by psychological and other psychosocial support services – including affirmative independent peer support and systemic advocacy services.

Medical interventions must not be approved as medically necessary by the decision-making forum on the basis of rationales based on gender stereotypes, social norms, family and cultural stereotypes and rationales, or financial rationales. This consequentially rules out arguments based on stigma and psychosocial rationales. Timing is not an appropriate rationale for non-urgent non-deferrable modifications to sex characteristics of children born with variations of sex characteristics.

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).

10 Regulation – Legal and policy prohibitions

10.1 Question 14: Prohibitions

“Should all non-emergency and/or deferrable medical interventions that alter a child's sex characteristics, where the child does not have legal capacity to consent, be prohibited by law? If so, should this prohibition be civil or criminal?”

We support the *Darlington Statement's* call for criminal prohibition of all non-deferrable medical interventions that alter a child's sex characteristics. We understand that this is a broader framework than that provided for in the terms of reference for this consultation, which focus on people born with variations in sex characteristics. It is acceptable for a prohibition to focus on people born (or suspected or perceived to be born) with variations in sex characteristics.

Such a prohibition would be consistent with the framing of unnecessary medical interventions on intersex children as harmful practices, in concluding observations to Australia issued by CEDAW (Committee on the Elimination of Discrimination against Women 2018).

We note that, like female genital mutilation, forced marriage, and the unnecessary sterilisation of people with disabilities, the Committee on the Elimination of Discrimination against Women has framed unnecessary medical interventions on intersex children as harmful practices. A criminal prohibition would be consistent with this framing.

Medical interventions to modify the sex characteristics of children should be notifiable procedures.

A legislated prohibition must be closely tied to two additional works in order to provide effective, holistic protections for people born with variations in sex characteristics:

- The development of human rights-affirming standards of care or guidelines for medical interventions on people born with variations of sex characteristics
- The provision of oversight for medical interventions where non-deferrable medical necessity and/or personal informed consent are asserted
- Public and clinical education on the needs of people born with variations in sex characteristics, human rights issues engaged by medical interventions, and relevant legislation and regulation.

11 Regulation – Clinical guidelines

11.1 Question 15: Current approaches

“What are the current approaches to the management of people born with variations in sex characteristics? What are these based on?”

11.1.1 2006 clinical consensus statement

A 2006 clinical “Consensus statement on management of intersex disorders” (Hughes et al. 2006; Houk et al. 2006) is typically taken as foundational in respect of the management of people born with variations in sex characteristics. However, the statement is sometimes taken as indicative merely of the existence of a clinical consensus (Carpenter 2018a; Kelly and Smith 2017). For example, the judge in the Family Court case *Re: Carla* cited the statement, but ignored its advice to monitor the gonads of a child with 17-beta hydroxysteroid dehydrogenase 3 (Family Court of Australia 2016; Carpenter 2018a; Kelly and Smith 2017).

As cited previously, the document itself relies upon physician feelings and beliefs to make assertions about parental distress and attachment (Hughes et al. 2006, 557). The document appears to have performed a role as a source of consensus despite such failings. As such, it did not require or lead to the creation of evidence to underpin clinical practices. A meeting six years later, in 2012, identified this continuing lack of evidence. Zillén, Garland and Slokenberga sum up the findings:

(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 (Zillén, Garland, and Slokenberga 2017)

This continues. A 2016 update to the clinical ‘consensus statement’, the ‘Global Disorders of Sex Development Update since 2006’ stated:

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 (Lee et al. 2016).

11.1.2 International Classification of Diseases

The World Health Organization’s *International Classification of Diseases* (ICD) version 11 Foundation also provides evidence of clinical practices. As discussed by Morgan Carpenter (2018c), the interventions described in the Family Court case *Re: Carla* closely align with the *ICD-11 Foundation* description for Carla’s diagnosis of 17-beta hydroxysteroid dehydrogenase 3. That code description states:

If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed. (World Health Organization 2018b)

This includes a gendered rationale for the sterilisation of Carla, in place of the cancer risk rationale described in the case (rationales which both run counter to a call for monitoring gonads made in the 2006 clinical “consensus statement”). This code description also precisely aligns with a statement in the Australasian Paediatric Endocrine Group submission to the Senate in 2013, that claimed such determinations of sex assignment were “in the past”:

In the past, it was thought that adequate penis size was the main determinant of whether an infant with ambiguous genitalia should be assigned male or female at birth (Australasian Paediatric Endocrine Group et al. 2013)

The contradictory nature of claims in such a diverse array of documents suggests little actual change to clinical practices, which are themselves facilitated by a “pick and mix” range of rationales.

11.1.3 Australian Capital Territory statements

Policy-makers may place too much significance on the role of the statement as a consensus document. For example, 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 (Gallagher 2014a).

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 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 (Gallagher 2014b).

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”, treating persons with “DSDs” as if they are a separate population to persons with intersex traits (Carpenter 2016).

11.1.4 2010 ethical principles

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 (Gillam, Hewitt, and Warne 2010). That framework claimed that psychosocial risks that can be minimised through medical intervention include parental bonding, marriage prospects and stigma relating to genital appearance (Gillam, Hewitt, and Warne 2010).

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 (A. Dreger, Sandberg, and Feder 2010).

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 (A. Dreger, Sandberg, and Feder 2010).

The methodology employed to develop the principles was described as reflective equilibrium, a concept developed by John Rawls. In the case of these guidelines, 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 (Gillam, Hewitt, and Warne 2011).

11.1.5 Victorian guidelines

In 2013, an 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 ethical framework is derivative of the 2010 principles by Gillam, Warne and Hewitt, and thus shares the same flaws. In particular, it permits surgical and other medical interventions for psychosocial rationales, it lacks evidence, and it lacks any provisions facilitating accountability and transparency. It 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 given adequate information, time or options to provide informed consent or make informed decisions on behalf of their children (Department of Health 2013).

No related provisions were made regarding redress, reparations or apology. However, these issues stated to be "in the past" in 2013 persist. In the same year, the Royal Children's Hospital Melbourne made a submission to the Senate committee inquiry arguing:

It is our opinion that early surgery has psychological benefits for the child, as it allows them to grow up with more normally appearing genitalia, which reduces psychosocial and psychological stigma associated with DSD and also minimises parental anxiety (Royal Children's Hospital Melbourne 2013)

This opinion also lacks evidence:

we acknowledge that outcomes related to current approaches remain to be established (Royal Children's Hospital Melbourne 2013)

In a 2018 article in *The Age* and *Sydney Morning Herald*, a representative of the hospital stated that:

it had no fixed position as every child was considered individually. "In each case, the RCH will consider the best available clinical evidence to work with the parents in determining the most appropriate treatment path for that child," ... "Parents are informed that differing opinions exist and are aware that deferring surgery is an option they can choose (Topsfield 2018)

Types of information disclosure are known to have a dramatic impact on decision-making.

In 2015, Victoria's Department of Health and Human Services published a *Neonatal eHandbook* 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...

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 (Department of Health and Human Services 2015a)

In March 2016, geneticist Jenny Graves cited the *eHandbook* as evidence for a "trend is to be supportive, conservative and avoid removing genital tissues if the condition is not life threatening" (Graves 2016). This was neither an adequate nor accurate form of evidence to justify this assertion.

This material was removed from the Department's website in April 2017 (Organisation Intersex International Australia 2017b), 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 (Carpenter and Organisation Intersex International Australia 2016). There is no evidence that the removal of this material from the Department's website has had any impact on clinical practices. Subsequent to this development, the Victorian intersex expert group developed a new version of that page, setting out what it believes should happen (Department of Health and Human Services 2015b).

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 virilised [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 (Department of Health & Human Services 2015).*

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:

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

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

This description matches the description for 'vulvoplasties' in Medicare and AIHW data (Carpenter 2018a; Department of Health 2014).

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. We do not support the guidelines as they do not provide human rights-based standards of care.

11.1.6 Queensland statements

In 2012, the Queensland government offered a reassurance regarding "past" practices, that:

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

In 2016, an anonymous government department from this state acted as *amicus* in the Family Court case *Re: Carla* (Family Court of Australia 2016). Subsequent to the decision in *Re: Carla*, the Queensland government 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. This 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 (Queensland Health 2016).

However, in addition to evidence of practices in the State designed to “enhance” children’s genitalia, sterilise them on the basis of gender stereotypes (Family Court of Australia 2016; Carpenter 2018c; Kelly and Smith 2017), and commence sex hormones inappropriate for a child’s gender identity (Family Court of Australia 2017; Topsfield 2018), concepts of “normal” are slippery. 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. Oll 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...

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 (Community Affairs References Committee, Senate of Australia 2013)

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

11.1.7 Statements against early interventions by Australian clinical bodies

In 2014, the Australian Medical Association stated, in a Position Statement Sexual and Reproductive Health:

Normalising cosmetic genital surgery on intersex infants should be avoided until a child can fully participate in decision making (Australian Medical Association 2014).

The Royal Australian and New Zealand College of Psychiatrists stated in a submission to the ALRC Family Law review in May 2018:

The RANZCP also notes its support of the Senate Community Affairs Reference Committee’s recommendation 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, considering the potential later-life implications that an involuntary procedure may have on an individual’s mental health (The Royal Australian and New Zealand College of Psychiatrists 2018).

While the RANZCP statement is flawed, because the Family Court has authorised medical interventions that fail to meet international human rights norms and failed to address the human rights implications of medical interventions that have occurred without Court oversight, the general principle is helpful.

These statements appear to have had no consistent or verifiable impact on clinical practices; human rights violations continue to take place.

11.1.8 The past, and claims of change to clinical practices

Claims that present practices have changed from those “in the past” have been made for so long that much evidence to the contrary exists.

Historical claims about practices “in the past” reveal that the same appeals have been made persistently: appeals for more research, appeals of improved techniques, appeals to greater openness, appeals of greater consideration of psychosocial issues, and appeals of fewer interventions. None have been supported by evidence. A sample follows.

In 1995, David Sandberg, a psychologist at “Buffalo Children’s Hospital’s Psychoendocrinology program” stated:

The urologists of my acquaintance would probably say that techniques have changed dramatically over the years, and that although the result of surgeries performed decades ago may have been very poor, that is no longer the case... You would be right to ask them “Where’s your data to prove that results today are superior to those in the past?” I concede that I have not been impressed with the quality of scientific publications purporting to provide such proof. The fact that they have not proved good results, however, does not prove that the results are poor. Much better outcome research on this topic is needed (D. Sandberg 1995).

Issues with lack of research nevertheless persist, as documented in the Council of Europe bioethics report (2017) and the global clinical update (Lee et al. 2016).

Journalist Rae Fry, in a discussion with Garry Warne, Sonia Grover, Milton Diamond and Chris Somers on Radio National’s *The Health Report* on 25 February 2002 stated that “in the past” information disclosure was limited:

Medical practice in intersex conditions is changing... In the past, some patients weren't told of their condition for years, sometimes not at all. These days there's more openness, which is important not only ethically, but because of ongoing health issues, like an increased risk of cancer and osteoporosis (Fry 2002).

We refer to the New Zealand Office of the Privacy Commissioner’s statement (2018) identifying variable change to this practice.

In 2003, Lih-Mei Liao describes how her multi-disciplinary clinic in London favoured psychological support. On surgery, attitudes “in the past” focused on functionality:

Whereas discussion of genital surgery has in the past typically (if not exclusively) emphasized functionality of female genitals as passive receptacle for the penis, within the current service, female desire, arousal and choices are emphasized (L. M. Liao 2003).

We refer to the Australasian Paediatric Endocrine Group Senate submission identifying “functional” rationales for surgery (2013). We also refer to the World Health Organization International Classification of Diseases (World Health Organization 2018b; Carpenter 2018c) and “technical” rationales for intervention.

In 2004, Crouch, Minto, Liao, Woodhouse and Creighton wrote that “Sexual function is an important area which has been neglected in the past” (Crouch, Naomi S. et al. 2004). In the same year, Frader and others stated in an article on “Health Care Professional and Intersex Conditions” that “in the past” interventions began prior to a child’s ability to assent or consent:

In the past, intervention has sometimes begun long before disclosure to or consultation with the child, despite a lack of physiologic justification (Frader J et al. 2004).

A broad range of evidence demonstrates the persistence of such interventions.

Oral testimony to a 2005 human rights investigation by the Human Rights Commission of the City and County of San Francisco by urologist Laurence Baskin reports that “in the past” there were too many surgeries:

Dr. Baskin said that in the past too many surgeries were performed, and that today irreversible surgeries are rare. He said, however, that 99 percent of the surgeries that are done are “very straightforward.” (Human Rights Commission of the City and County of San Francisco and de María Arana 2005, 51)

In 2018, Baskin testified against a resolution in the Senate of California condemning early unnecessary surgeries on intersex children. Littlefield reports claims not of reduced numbers, but instead a defence of their application; of “restoring normal” sex characteristics to make each individual “a functional member of society”:

“These are not gender-reaffirming surgeries ... these are children who have congenital anomalies like a cleft palate ... that’s fixed,” Dr. Larry Baskin, chief of pediatric urology at the University of California San Francisco, said during a June 12 hearing on the California resolution. “We’re restoring normal anatomy.” ...

“Our focus is to make sure that each person becomes a functional member of society,” Baskin said at a May 1 hearing. “In other words, they have a community

that they are involved in, and they can be productive, and in California pay taxes, that's the way I would define that." (Littlefield 2018)⁷

In 2007, Yang, Felsen and Poppas wrote that surgical interventions on children's clitorises have undergone many changes "in the past":

Surgical correction of the enlarged clitoris has undergone many changes in the past 3 decades. Initially, clitoridectomy was performed. Recession clitoroplasty was later devised as an alternative. Today, reduction clitoroplasty, where the glans is preserved and part of the erectile bodies are excised, is the most widely accepted and used technique.³ Despite advancements in surgical technique controversy persists regarding the viability and sensitivity of the clitoris following reduction clitoroplasty (Yang, Felsen, and Poppas 2007)

This paper also revealed that children subjected to "reduction clitoroplasty" were also subjected to clitoral sensitivity testing ("CST"):

Patients older than 5 years were considered candidates for CST. CST was performed using a cotton tip applicator. Using a scale of 0 —no sensation to 5— maximum sensation, the patient was asked to report the degree of sensation at various points of the inner thigh and genitalia (labia majora, labia minora, vaginal introitus and clitoris). Inner thigh stimulation was set at level 3 for each patient and used as a baseline to compare other areas tested. In addition, these patients also had vibratory sensory testing performed using a biothesiometer designed to quantify the ability of patients to detect vibratory stimuli.

These interventions are abhorrent, but demonstrate the experimental nature of early medical interventions. They are violations of children's rights.

Katrina Karkazis in 2008 found that procedures have changed "in the past", but that technical procedure "improvements" are conflated with outcome "improvements":

A common tendency among clinicians, particularly among surgeons, is to conflate improvements in medical techniques with improvements in outcome. A procedure that is easier and more efficient for the surgeon is assumed to produce a better result for the patient. Dr. O says, "In the past three years, vaginoplasty has changed tremendously. I wasn't satisfied with how we did vaginoplasties before, because the vagina was inadequate, so you couldn't have normal penetration. Now we can make an adequate vagina." (Karkazis 2008)

Indeed, claims of changes to clinical practices persist. Most amount to no more than vague assurances. The experience in Queensland, with assurances of changed practices and

⁷ In response: "Kyle Knight, co-author of the Human Rights Watch report, said such comments bring to light the pejorative way urologists have talked about intersex people in pay-walled medical journals for decades. 'Is someone doing TurboTax with their clitoris?' Knight said in an interview with *Rewire.News*. 'What is he talking about? But that's where the discourse has been at—that is where the 'medicine' has been at for 20 years. It's just coming out in public now.'"

medical interventions only in cases of “serious risk” to health, demonstrates the lack of merit in unsubstantiated claims of change to clinical practices. Evidence from Victoria is similarly inconsistent. The Australasian Paediatric Endocrine Group advised the Senate in 2013 that:

In the past, it was thought that adequate penis size was the main determinant of whether an infant with ambiguous genitalia should be assigned male or female at birth. (Australasian Paediatric Endocrine Group et al. 2013).

As previously stated, this idea remains directly relevant to the 2016 Family Court case *Re: Carla* and selected statements in the *International Classification of Diseases* version 11 Foundation, in 2018.

One clinical contact recently suggested that surgeons are “far less likely to do mutilatory surgery than in the past”, suggesting either a persistent focus on surgical technique ahead of necessity, or a recognition that fewer “mutilatory” interventions take place – analogous to an argument that fewer female genital mutilations take place.

The Human Rights Watch/interACT study in the US found that:

While published data show that medically unnecessary surgeries are being conducted on intersex children, practitioners interviewed for this report often reported that they observed general trends towards doing fewer surgeries (though they did not always specify which procedures) (Human Rights Watch 2017, 49)

However, an endocrinologist on a DSD team at a regional referral hospital said that while she observed many of her peers in DSD care speaking publicly about a decrease in medically unnecessary surgeries on intersex children: “Most patients at our center have cosmetic surgery to their external genitalia.” ... This doctor also reported reviewing unpublished data indicating that medically unnecessary surgeries remain more widespread than many doctors acknowledge (Human Rights Watch 2017, 52).

As mentioned earlier, a recent clinical systemic review, by clinicians at the Centre for Research in Evidence-Based Practice, Faculty of Health Sciences and Medicine, Bond University, has also found that clinicians “rarely had accurate expectations of benefits or harms”, and “more often underestimated rather than overestimated harms and overestimated rather than underestimated benefits” (Hoffmann and Mar 2017). Charitably, claims of changed practices may represent a similarly optimistic outlook, but they lack merit when not substantiated.

Individual clinical teams make casuistic decisions, with no guarantee of consistency at hospital, State/Territory or Commonwealth levels. Neither historic practices nor current practices have been clearly and transparently established, at any of these levels. As a consequence, no change can be established. No point at which the past described in clinical papers became the present can be established. No apology has been made for what

happened “in the past”, and no redress has been made; these would lack meaning when there is evidence from Family Court cases, media reports and confidential sources that practices “in the past” continue to the present. Thus, claims that certain practices are “in the past” lack rigor, are not generalisable. In their multiplicity and contradictions, and when compared to evidence from the Family Court and statistical data, such claims are troubling.

Recent studies in Germany (Klöppel 2016), the UK (Monro et al. 2017) and US (Human Rights Watch 2017) show no evidence of a decline in number of surgeries. Recent US paediatric articles show high rates of surgeries amongst children (Nokoff et al. 2017; Ellens et al. 2017). There is no clear understanding of what happens nationally in Australia. Reports from individual centres such as the major hospitals and hospital networks in Sydney and Melbourne lack substance or evidence, relying instead on assurances and beliefs of change and consideration of the issues. There have been many fine statements, principles and guidelines, but none of them are binding.

Clinical attitudes towards practices in the past are made with insufficient historical analysis and understanding of the history of medicine’s attitudes towards people with intersex bodies. They appear intended to reassure without disclosure or transparency; to maintain an obfuscated status quo where the human rights of people born with variations in sex characteristics do not guide clinical practice. As such, clinical claims about the past are not fit for purpose.

Yet, the past does provide valuable and distinct perspectives. Papers by Elizabeth Reis (2012) and Alice Dreger (2003) present a much more comprehensive analysis. The role of medicine in constructing both surgical “normality” and “other” identities is detailed in a paper by Morgan Carpenter (2018a). A 1966 *Medical Journal of Australia* case illustrates a clinical transition from adult surgeries with consent to childhood surgeries. In 2005, Hazel Beh and Milton Diamond cited a paper by Jorge Daaboul, “Does the Study of History Affect Clinical Practice? Intersex as a Case Study: The Physician’s View” that stated:

History, however, provides strong empirical evidence that, in the past, intersexed individuals have lived normal, happy lives without medical treatment. The empirical evidence derived from the study of history complements and gives practical weight to the ethical proposition that individuals with intersex have a right to autonomously decide their futures and be free from medical intervention (Beh and Diamond 2005).

Present and past assurances, together with a lack of transparency, non-adherence to statements and principles, and variability, mean that self-regulation has failed. Without some kind of sanction or penalty for noncompliance or non-adherence, and without associated oversight and transparency, change to clinical practices will not happen.

11.2 Question 16: Best practice guidelines

“Do any medical guidelines exist that are considered best practice in Australia or internationally, either for the general management of people born with variations in sex characteristics, or for specific variations?”

In general, available guidelines to date suffer from their nonbinding character, lack of evidence of implementation, and evidence of continued harmful practices.

11.2.1 Accord Alliance guidelines

When Zillén, Garland and Slokenberga wrote for the Council of Europe’s Commission on Bioethics that no clinically-accepted standard of care:

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

They excluded as not clinically-accepted a framework published in 2006 by the Accord Alliance, a successor to ISNA. This was consequential to the “consensus statement on management of intersex disorders”. The “Clinical guidelines for the management of disorders of sex development in childhood” also suffered from a lack of acceptance from established intersex advocates – a number of whom are named in a disclaimer on page 3 as opposing the term “disorders of sex development”. The guidelines comment that:

*These guidelines begin with the commonly-held assumption that the goal of DSD treatment is the long-term physical, psychological, and sexual well-being of the patient. This approach is therefore termed “patient-centered.” ... It is critical, therefore, to emphasize that **it is more important to focus on providing patient-centered care than to create and maintain a multidisciplinary team precisely as described** in the following. Although dedicated multidisciplinary teams which focus on patients’ psychosocial well-being may be more likely than alternatives to provide optimal care, **a dedicated multidisciplinary team is neither a guarantor of nor a necessity of patient-centered care for DSDs** (Consortium on the Management of Disorders of Sex Development et al. 2006).*

The guidelines are dated and have many limitations:

- They include no consideration of the human rights implications of medical interventions. Indeed, they ignore the existence of human rights frameworks, including the concept of bodily integrity. Discussion of the clinical concept of autonomy is also very limited.
- The expressed “patient-centered” model requires that intersex people be patients.
- Social issues are only addressed when necessary.
- Ideas of sex and gender have not kept pace with social and legal developments; this includes an idea that someone with a specific variation will have a specific gender identity.
- They do not address conflicting rationales evident in the contemporaneous “consensus statement on management of intersex disorders”. For example, they do not address identity-based and psychosocial rationales in the “consensus statement such as “minimizing risk of gender identity confusion”.⁸

⁸ Thanks to Mauro Cabral Grinspan for analysis of these guidelines.

11.2.2 Maltese guidelines

Malta legislated in 2015 for a working group to develop national guidelines, and for establishment of an inter-disciplinary/oversight team. We understand, from communication with the Director of the Human Rights and Integration Directorate of the Ministry for European Affairs and Equality, that these tasks have not yet commenced but are a current focus of action.

11.2.3 interACT/Lambda Legal hospital guidelines

In the US, interACT and Lambda Legal have developed new hospital guidelines. These appear closely tied to local legislation and regulation in the US (Lambda Legal and interACT 2018). Unlike the 2006 guidelines for the management of DSDs in childhood, these address human rights issues raised by medical interventions. For example, they ask hospitals to “ensure that the intersex youth does **not** undergo any medical procedure or treatment related to an intersex trait unless” urgent or capable of informed assent, as assessed by a mental health professional (Lambda Legal and interACT 2018). Some guidance on the provision of informed consent is provided.

Overall, these guidelines are opt-in and non-binding. If transposed to the Australian context, they would have no guarantee of evidencable impact, any more than previous statements, principles and guidelines.

11.3 Questions 17 and 18: National guidelines

“Should there be national guidelines to guide medical interventions involving people born with variations in sex characteristics?”

“If so: what factors should the guidelines take into account? what should be the legal status of the guidelines? what should be the process, including consultation, for drafting the guidelines? what should be the oversight mechanism for decisions made under the guidelines?”

Yes, there should be national standards of care or guidelines. To be effective, such standards of care/guidelines need to be developed in ways that, as core principles:

- affirm and meet human rights norms, including as expressed in concluding observations to Australia by UN Treaty Bodies such as the Human Rights Committee and Committee on the Elimination of Discrimination Against Women
- are led by a human rights expert, such as a past Human Rights Commissioner or Secretary
- benefit from effective, meaningful, and resourced participation by intersex-led organisations including IHRA and AISSGA
- benefit from a range of different clinical perspectives and specialisms, including clinicians working with adults, infants, children and adolescents with variations of sex characteristics, parents and prospective parents

Ideally, a standards/guideline development body should have access to accurate information on current and historic practices.

National standards of care or guidelines should set out, *inter alia*:

- Information for hospitals and clinical teams on the human rights impacted by clinical decision-making.
- Information on types of rationales and procedures that should be deferred until such a time as an individual can determine if or when they wish to proceed.
- Oversight practices regarding procedures where either non-deferrable medical necessity/urgency or personal informed consent are asserted.
- Criteria and suggested content for information disclosure to parents and carers, and individuals with variations of sex characteristics
- Access to reparative interventions
- Access to redress for individuals subjected to relevant medical interventions without their informed consent

Mechanisms to develop standards of care/guidelines need to include human rights and child rights experts, and representatives of independent intersex-led organisations; we strongly recommend including representatives of IHRA and the AISSGA. An oversight mechanism must operate in such a way that it affirms human rights norms, as expressed by UN Treaty Bodies including the Human Rights Committee and Committee on the Elimination of Discrimination Against Women.

Additionally, standards of care/guidelines need to either have legal standing, or be accompanied by legislative protections from unnecessary procedures, in order to provide effective and meaningful penalties for noncompliance. Without such penalties, national standards of care/guidelines are unlikely to have effect any more than guidelines, statements and principles produced in the past.

Changes to statutes of limitations may also be required, to ensure access to redress.

12 Lack of data

12.1 Questions 19 and 20: Data sources and adequacy

“What are the current Australian sources of data on: the number and nature of medical interventions involving people born with variations in sex characteristics? long-term outcomes of medical interventions involving people born with variations in sex characteristics? long-term outcomes of people born with variations in sex characteristics not undertaking medical interventions?”

“How adequate are the current Australian sources of data for each of these areas?”

In our view, *disclosure* of available data is inadequate.

As discussed above, limited data is available (Carpenter 2018a) through the Department of Health and Australian Institute of Health and Welfare. These data do not clearly and

unambiguously identify all relevant medical interventions. The Department of Health may be able to obtain better quality information from raw data sources.

However, it appears that data on procedures and diagnoses is sensitive. Allocation to procedure costs is value-laden. Available data may not be able to account for any displacement of procedures from politically sensitive categories to less politically sensitive categories. Reports from Germany appear to show a shift from specific to general classifications, perhaps in acknowledgement of contention (Klöppel 2016; Carpenter 2018a).

12.2 Question 21: Barriers to data collection

“What barriers exist to nationally consistent data collection?”

We believe that the primary concerns with collecting and accessing nationally consistent data on historical and current practices are matters of policy and political sensitivity, and not resourcing. Lack of transparency, and unevidenced appeals to assurances of changed clinical practices, favour the status quo.

13 Privacy

13.1 Question 22: Respecting privacy

“How can medical practices best respect the privacy of people born with variations in sex characteristics?”

Kirsten Sandberg identifies the right to privacy as being engaged by medically unnecessary interventions on people born with variations in sex characteristics. She comments:

The child’s right to private life is regulated in article 16 CRC, stating that the child should not be subjected to arbitrary or unlawful interference with his or her privacy. The medical process of sex assignment does not only include surgery and medication but extensive and repeated examinations of intimate parts of the body. Again, this may be necessary as part of a medical process which may all in all be in the best interests of the child, but only within strict limits (K. Sandberg 2018)

We also draw the Commission’s attention to:

- A 2018 statement by the New Zealand Office of the Privacy Commissioner on handling health information of intersex individuals (Office of the Privacy Commissioner 2018).
- A 2018 submission by IHRA and AISSGA to the Medical Board of Australia on “Draft revised guidelines Sexual boundaries in the doctor-patient relationship” (Carpenter and Hart 2018).

13.2 Question 23: Accessing records

“Have you faced any difficulties accessing your medical records?”

We are aware of individuals whose records have been misplaced or lost, including loss attributed to adverse weather events.

Within limited resourcing constraints, IHRA has sought to assist some individuals with the recovery of medical records. On one occasion IHRA enlisted the assistance of a State health minister via a letter to the treating public hospital. Access to medical records in this case did not eventuate.

13.3 Question 24: Improving access to records

“How can access to medical records and histories be improved?”

Childhood records could be maintained for the lifetime of the individual. Penalties should be introduced to prevent future cases of loss or damage to medical records.

14 Access to support services and peer support

We support the *Darlington Statement*, including its demands in relation to peer support:

39. We recognise the **trauma and mental health concerns** caused by the unnecessary medicalisation of intersex people, as well as stigmatisation of intersex characteristics that has resulted in a legacy of isolation, secrecy and shame.
40. We recognise the fundamental importance and benefits of **affirmative peer support** for people born with variations of sex characteristics.
41. Our peer support organisations and other peer communities need resourcing and support to **build communities and networks** inclusive of all intersex people. No intersex person or parent of an intersex child should feel they are alone, irrespective of their bodily variation or the language they use.
42. We recognise the needs and lived experience of **youth**, and of people coming from varied **cultural and faith backgrounds**. We recognise these experiences as valid and legitimate.
43. We recognise the fundamental importance and benefits of **peer support for parents, caregivers, and families** of people with variations of sex characteristics. We recognise the importance and benefits of **peer support for friends, partners, and others** who support intersex people in their day-to-day lives.
44. **Peer support must be integrated** into human rights-based multi-disciplinary medical approaches, teams and services.
45. We call for **public, governmental, and philanthropic support** for funded, affirmative peer support.
46. We acknowledge that intersex people are the **experts** on our own lives and lived experience. Intersex people are experts in understanding the long term

effects of medicalisation and medical interventions. (Androgen Insensitivity Syndrome Support Group Australia et al. 2017)

14.1 Question 25: Supporting individuals and families

“How can people born with variations in sex characteristics and their families and carers be more adequately supported?”

Rhetoric about the uniqueness of each case, and individualised decision-making acts against statements calling for access to peer support. Individualising decision-making suggests that family and individual needs are distinct; that families and individuals with different intersex variations do not share anything in common. It justifies their isolation; not putting families in contact with peers.

We believe that independent and affirmative peer support, and advocates working on systemic and individual issues, should be integrated into multidisciplinary teams. Medical sociologist and former AIS-DSD president Georgiann Davis states:

What my research and experience with intersex organizations in the U.S. reveal is that there is often resistance to organizational change by organizational members who have been psychologically and unethically harmed by medical professionals who frame intersex as a medical emergency rather than a natural bodily variation (Davis 2018).

In the period 2014-2015, the AIS-DSD Support Group opened up to intersex people of all genders, and parents, through addressing concerns that individuals needed space to connect with similarly situated individuals.

Parents may not wish for a child’s sex or gender questioned, especially where these might call a child’s history of medical interventions into doubt. Eric and Stephani Lohman, parents of a child with CAH, have described how:

We quickly found that parent and advocacy groups associated with our child’s specific condition were deficient sources of information on raising a surgery-free child. This is partly due, we suspect, to the fact that several prominent pediatric urological surgeons are affiliated directly... The general impression we got from these organizations was that, if we wanted avoid surgery they supported that choice, so long as we kept that decision to ourselves. We were unable to find any other parents on social media or otherwise that had children born with similar conditions who had opted against a cosmetic genital procedure in infancy (we have since found fewer than ten families, almost all of whom choose to remain discreet about their decision) (Lohman, Lohman, and Davis 2018, 17–18)

There is a risk that parent-led groups may, then, be dominated by narrow clinical perspectives and accompanied by fears, often driven by clinical narratives that lack evidence and, in the Lohman’s case proposed not surgery or no surgery but one type of surgery or another (Lohman, Lohman, and Davis 2018, 86–90). Parents may also be led to fear straw

men in the intersex movement, such as the idea that intersex is an identity category and medical interventions can prevent their child from forming such an identity.

By affirmative, we refer to organisations open to people born with variations in sex characteristics that may or may not be for people with specific diagnoses, but that are open to all individuals with those diagnoses or variations irrespective of gender identity, and terminology preference.

14.2 Question 26: Integrating peer support into decision-making

“How can psychological and peer support be more integrated into decision making processes?”

Independent and affirmative peer support, and advocates working on systemic and individual issues, should be integrated into groups developing standards of care, and into effective, independent oversight bodies.

Where interventions are performed on intersex minors with capacity to consent, intersex human rights defenders recommend that such consent must be fully informed, with individuals and families having access to funded, independent counselling and peer support. This is predicated on the beliefs that peer support needs to be independent and affirm human rights norms, and that parents need access to peers in order to make good decisions.

14.3 Question 27: Barriers to connecting individuals to services

“What barriers exist to connecting individuals to support services?”

Use of technical language by clinicians may prevent individuals and families from accessing support services that use affirmative language.

Physicians, LGBT groups and media may describe intersex in ways that differ from the ways that intersex-led organisations and the *Darlington Statement* use the term, and describe intersex people in ways that differ from the diverse ways we understand ourselves. In some instances, this appears to be intended to reassert clinical authority over intersex bodies as pathologised (Carpenter 2018a).

Physicians may refer individuals and families to overseas institutions in preference to local groups. This can reinforce isolation and a belief in the rareness of individual intersex variations.

Individuals with gender identities and terminological preferences are frequently excluded from support groups.

No long-term follow-up takes place in Australia (Australasian Paediatric Endocrine Group et al. 2013), this is complex given a clinical history of concealment. 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:

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 (S. M. Creighton et al. 2014).

14.4 Question 28: Barriers in accessing services

“What barriers exist for individuals in accessing support services?”

Resourcing constraints greatly impact on the ability of intersex-led organisations to offer services directly to individuals across Australia. To an extent, this appears to be because policy-makers believe that the needs of intersex populations are met by ‘LGBTI’ services focused on the needs of individuals able to express agency about their sexual or gender identity (Carpenter 2018a).

Resourcing for LGBTI services and organisations has not been translated into resourcing for intersex-led organisations to provide peer support and systemic advocacy services for individuals irrespective of age, sexual orientation and gender identity, and our families. Lack of funded, independent and affirmative services for people born with variations of sex characteristics and their families has consequences.

14.5 Question 29: Resourcing support

“How can peer support groups and organisations be adequately resourced and supported?”

Intersex-led peer support and systemic advocacy organisations must be supported by Commonwealth and State/Territory governments, and philanthropic sources, independent of, and in addition to, any support given by those institutions for LGBTI and disability organisations.

15 References

- Amnesty International. 2017. 'First, Do No Harm'. EUR 01/6086/2017. London: Amnesty International.
- Androgen Insensitivity Syndrome Support Group Australia, Intersex Trust Aotearoa New Zealand, Organisation Intersex International Australia, Eve Black, Kylie Bond, Tony Briffa, Morgan Carpenter, et al. 2017. 'Darlington Statement'. Sydney, New South Wales. <https://darlington.org.au/statement>.
- Angier, Natalie. 1996. 'Intersexual Healing: An Anomaly Finds a Group'. *The New York Times*, 4 February 1996. <http://www.nytimes.com/1996/02/04/weekinreview/ideas-trends-intersexual-healing-an-anomaly-finds-a-group.html>.
- Attorney General's Department. 2013. 'Review of Australia's Female Genital Mutilation Legal Framework - Final Report'. Attorney General's Department. <http://www.ag.gov.au/Publications/Pages/ReviewofAustraliasFemaleGenitalMutilationLegalFramework-FinalReportPublicationandforms.aspx>.
- . 2015. 'Australian Government Response to the Senate Community Affairs References Committee Reports on Involuntary or Coerced Sterilisation'. Attorney General's Department.
- . 2018. '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'. CRC/AUS/5-6.
- Australasian Paediatric Endocrine Group, Jacqueline Hewitt, Garry Warne, Paul Hofman, and Andrew Cotterill. 2013. 'Submission of the Australasian Paediatric Endocrine Group to the Senate Inquiry into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development'. Submission. <http://www.aph.gov.au/DocumentStore.ashx?id=aafe43f3-c6a2-4525-ad16-15e4210ee0ac&subId=16191>.
- Australia. 2015. *Sex Discrimination Act 1984*. <https://www.comlaw.gov.au/Details/C2015C00275/Download>.
- . 2018. *Family Law Act 1975 (Volume 2)*. https://www.legislation.gov.au/Details/C2018C00003/Html/Volume_1, <http://www.legislation.gov.au/Details/C2018C00003>.
- Australian Human Rights Commission. 2018. *Protecting the Human Rights of People Born with Variations in Sex Characteristics in the Context of Medical Interventions Consultation Paper*. Sydney: Australian Human Rights Commission.
- Australian Medical Association. 2014. 'AMA Position Statement Sexual and Reproductive Health 2014'. https://ama.com.au/sites/default/files/documents/position_statement_on_sexual_and_reproductive_health_2014_0.pdf.
- Bailey, Rebecca J. 1979. 'Family Law—Decree of Nullity of Marriage of True Hermaphrodite Who Has Undergone Sex-Change Surgery'. *Australian Law Journal* 53 (9): 659–65.
- Baratz, Arlene B., and Ellen K. Feder. 2015. 'Misrepresentation of Evidence Favoring Early Normalizing Surgery for Atypical Sex Anatomies'. *Archives of Sexual Behavior* 44 (7): 1761–63. <https://doi.org/10.1007/s10508-015-0529-x>.

- Beh, Hazel Glenn, and Milton Diamond. 2005. 'David Reimer's Legacy: Limiting Parental Discretion'. *Cardozo Journal of Law and Gender* 12: 5–30.
- Bock, Andrew. 2013. 'It Takes More than Two'. *The Age*, 20 June 2013. <http://www.theage.com.au/national/it-takes-more-than-two-20130619-2oj8v.html>.
- Briffa, Tony. 2004. 'Intersex Surgery Disregards Children's Human Rights'. *Nature* 428 (April): 695. <https://doi.org/10.1038/428695a>.
- Bryant, Diana, and Family Court of Australia. 2013. 'Submission to the Senate Community Affairs Committee Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia', 22 February 2013.
- Carmack, Adrienne, Lauren Notini, and Brian Earp. 2015. 'Should Surgery for Hypospadias Be Performed Before an Age of Consent?' *Journal of Sex Research* 53 (8): 1047–58. <https://doi.org/10.1080/00224499.2015.1066745>.
- Carpenter, Morgan. 2016. 'The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change'. *Reproductive Health Matters* 24 (47): 74–84. <https://doi.org/10.1016/j.rhm.2016.06.003>.
- . 2017. 'Re Carla (Medical Procedure) [2016] FamCA 7'.
- . 2018a. 'The "Normalisation" of Intersex Bodies and "Othering" of Intersex Identities'. In *The Legal Status of Intersex Persons*, edited by Jens Scherpe, Anatol Dutta, and Tobias Helms, 445–514. Cambridge, England: Intersentia. <http://intersentia.com/en/the-legal-status-of-intersex-persons.html>.
- . 2018b. 'Submission to the Expert Panel on Religious Freedoms'.
- . 2018c. 'Intersex Variations, Human Rights, and the International Classification of Diseases'. *Health and Human Rights* 20 (2). <https://www.hhrjournal.org/2018/08/intersex-variations-human-rights-and-the-international-classification-of-diseases/>.
- . 2018d. 'Intersex People: Not Invisible in Sport but Inadvertently Excluded'. *Play by the Rules* (blog). 13 September 2018. <https://www.playbytherules.net.au/resources/articles/intersex-inclusion>.
- Carpenter, Morgan, and Bonnie Hart. 2018. 'Draft Revised Guidelines Sexual Boundaries in the Doctor-Patient Relationship', 3 March 2018. <http://www.medicalboard.gov.au/documents/default.aspx?record=WD18%2f24780&dbid=AP&chksum=f5EcfqvFcBhqtv4aGRwmbw%3d%3d>.
- Carpenter, Morgan, and Organisation Intersex International Australia. 2016. 'Contribution to the List of Issues Prior to Reporting to the Committee against Torture for Australia'. Sydney: Organisation Intersex International Australia. <https://oii.org.au/30546/loi-cat-review/>.
- . 2017a. 'Shadow Report Submission to the Committee on the Rights of Persons with Disabilities on the Situation of Intersex People in Australia'. INT/CRPD/ICS/AUS/28302. <https://oii.org.au/31467/submission-crpd-2017/>.
- . 2017b. 'Shadow Report Submission to the Human Rights Committee on the Situation of Intersex People in Australia'. INT/CCPR/CSS/AUS/28771. <https://oii.org.au/31568/shadow-report-iccpr-2017/>.
- Center for Drug Evaluation and Research, and Food and Drug Administration. 2016. 'FDA Drug Safety Communication: FDA Review Results in New Warnings about Using General Anesthetics and Sedation Drugs in Young Children and Pregnant Women'. WebContent. 14 December 2016. <http://www.fda.gov/Drugs/DrugSafety/ucm532356.htm>.

- Chase, Cheryl. 1998. 'Surgical Progress Is Not the Answer to Intersexuality'. *Journal of Clinical Ethics* 9 (4): 385–92.
- Committee against Torture. 2016. 'List of Issues Prior to Submission of the Sixth Periodic Report of Australia'. CAT/C/AUS/QPR/6. Geneva: United Nations.
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CAT%2fC%2fAUS%2fQPR%2f6&Lang=en.
- . 2017. 'List of Issues Prior to Submission of the Sixth Periodic Report of Australia'. CAT/C/AUS/QPR/6. Geneva: United Nations.
- Committee on Civil and Political Rights. 2014. 'General Comment No. 35: Article 9 (Liberty and Security of Person)'. CCPR/C/GC/35.
- Committee on Economic, Social and Cultural Rights, and United Nations. 2017. 'Concluding Observations on the Fifth Periodic Report of Australia (Advance)'. E/C.12/AUS/CO/5.
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=E%2fC.12%2fAUS%2fCO%2f5&Lang=en.
- Committee on the Elimination of Discrimination against Women. 2018. 'Concluding Observations on the Eighth Periodic Report of Australia'. CEDAW/C/AUS/CO/8.
- Committee on the Elimination of Discrimination against Women, and Committee on the Rights of the Child. 2014. 'Joint General Recommendation No. 31 of the Committee on the Elimination of Discrimination against Women/General Comment No. 18 of the Committee on the Rights of the Child on Harmful Practices'. CEDAW/C/GC/31-CRC/C/GC/18.
- Committee on the Rights of Persons with Disabilities. 2014. 'General Comment No. 1, Article 12: Equal Recognition before the Law'. CRPD/C/GC/1. Geneva: United Nations.
http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en.
- . 2016. 'General Comment No. 3, on Women and Girls with Disabilities'. CRPD/C/GC/3. Geneva: United Nations.
- . 2017. 'List of Issues Prior to the Submission of the Combined Second and Third Periodic Reports of Australia'. CRPD/C/AUS/QPR/2-3. Geneva: United Nations.
- . 2018. 'General Comment No 6: Article 5: Equality and Non-Discrimination'. CRPD/C/GC/6. Geneva: United Nations.
- Committee on the Rights of the Child. 2011. 'General Comment 13: Article 19: The Right of the Child to Freedom from All Forms of Violence'. CRC/C/GC/13.
- . 2013. '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)'. CRC/C/GC/14.
- . 2016. 'Concluding Observations on the Fifth Periodic Report of New Zealand'. CRC/C/NZL/CO/5. Geneva: United Nations.
- Community Affairs References Committee, Senate of Australia. 2013. *Involuntary or Coerced Sterilisation of Intersex People in Australia*. Canberra: Community Affairs References Committee.
http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index.
- Conn, Jennifer, Lynn Gillam, and Gerard Conway. 2005. 'Revealing the Diagnosis of Androgen Insensitivity Syndrome in Adulthood'. *BMJ* 331 (7517): 628–30.
<https://doi.org/10.1136/bmj.331.7517.628>.
- Consortium on the Management of Disorders of Sex Development, California Endowment, Arcus Foundation, and Tides Foundation. 2006. *Clinical Guidelines for the*

- Management of Disorders of Sex Development in Childhood*. Whitehouse Station, N.J.: Accord Alliance, c2008.
- Cools, M, A Dessens, S Drop, J Hewitt, and G Warne. 2013. 'Answers to Questions on Notice (Received 27 Sep 2013)'. In *Chapter 4: Intersex and Cancer. Involuntary or Coerced Sterilisation of Intersex People in Australia*. Parliament of Australia. http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index.
- Creighton, Sarah. 2016. 'Surgical Management of DSD: New Insights', August. <http://abstracts.eurospe.org/hrp/0086/hrp0086con1.2.htm>.
- Creighton, Sarah M., Lina Michala, Imran Mushtaq, and Michal Yaron. 2014. 'Childhood Surgery for Ambiguous Genitalia: Glimpses of Practice Changes or More of the Same?' *Psychology and Sexuality* 5 (1): 34–43. <https://doi.org/10.1080/19419899.2013.831214>.
- CRIN. 2018. 'The Three Ws of Children's Bodily Integrity'. *And Beyond* (blog). 28 August 2018. <https://medium.com/and-beyond/the-three-ws-of-childrens-bodily-integrity-13a46f997908>.
- Crouch, Naomi S., Catherine L. Minto, Lih-Mei Liao, C R J Woodhouse, and Sarah M. Creighton. 2004. 'Genital Sensation after Feminizing Genitoplasty for Congenital Adrenal Hyperplasia: A Pilot Study'. *BJU International* 93: 135–38. <https://doi.org/10.1046/j.1464-410X.2004.04572.x>.
- Davis, Georgiann. 2011. "'DSD Is a Perfectly Fine Term": Reasserting Medical Authority through a Shift in Intersex Terminology'. In *Advances in Medical Sociology*, edited by PJ McGann and David J Hutson, 12:155–82. Bingley: Emerald Group Publishing. [https://doi.org/10.1108/S1057-6290\(2011\)0000012012](https://doi.org/10.1108/S1057-6290(2011)0000012012).
- . 2015. *Contesting Intersex: The Dubious Diagnosis*. Biopolitics. NYU Press.
- . 2018. 'Re: Resistance to Organizational Change', 11 September 2018.
- Dayner, Jennifer E., Peter A. Lee, and Christopher P. Houk. 2004. 'Medical Treatment of Intersex: Parental Perspectives'. *The Journal of Urology* 172 (4): 1762–65. <https://doi.org/10.1097/01.ju.0000138519.12573.3a>.
- Deans, R., M. Berra, and S.M. Creighton. 2010. 'Management of Vaginal Hypoplasia in Disorders of Sexual Development: Surgical and Non-Surgical Options'. *Sexual Development* 4 (4–5): 292–99. <https://doi.org/10.1159/000316231>.
- Delimata, Natalie, Margaret Simmonds, Michelle O'Brien, Georgiann Davis, Richard Auchus, and Karen Lin-Su Lin-Su. 2018. 'Evaluating the Term "Disorders of Sex Development": A Multidisciplinary Debate'. *Social Medicine* 11 (3): 98–107. <http://socialmedicine.info/index.php/socialmedicine/article/view/932>.
- Department of Communities. 2012. 'Engaging Queenslanders: A Guide to Working with Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Communities'. 2896-11 FEB12.
- Department of Health. 2013. 'Decision-Making Principles for the Care of Infants, Children and Adolescents with Intersex Conditions'. 50 Lonsdale Street, Melbourne: Victorian Government. <http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions>.
- . 2014. 'MBS Reviews Vulvoplasty Report'. Department of Health. [http://www.health.gov.au/internet/main/publishing.nsf/content/E393B5FFC597840OCA257EB9001EEC59/\\$File/Vulvoplasty_Review_Report.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/E393B5FFC597840OCA257EB9001EEC59/$File/Vulvoplasty_Review_Report.pdf).

- Department of Health & Human Services. 2014. 'Congenital Adrenal Hyperplasia (CAH) (2 June 2017)'. August 2014. <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/congenital-adrenal-hyperplasia-cah>.
- . 2015. 'Congenital Adrenal Hyperplasia (CAH) in Neonates (2 June 2017)'. 16 October 2015. <https://www2.health.vic.gov.au:443/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-e handbook/conditions/congenital-adrenal-hyperplasia>.
- Department of Health and Human Services. 2015a. 'Ambiguous Genitalia in Neonates'. 16 October 2015. <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-e handbook/congenital-abnormalities/ambiguous-genitalia>.
- . 2015b. 'Ambiguous Genitalia in Neonates (2017)'. 16 October 2015. <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/perinatal-reproductive/neonatal-e handbook/congenital-abnormalities/ambiguous-genitalia>.
- Dreger, Alice Domurat. 2003. *Hermaphrodites and the Medical Invention of Sex*. 4. print. Cambridge, Mass.: Harvard Univ. Press.
- Dreger, Alice, David E. Sandberg, and Ellen K. Feder. 2010. 'From Principles to Process in Disorders of Sex Development Care'. *Hormone Research in Paediatrics* 74 (6): 419–20. <https://doi.org/10.1159/000316943>.
- Earp, Brian. 2016. 'In Defence of Genital Autonomy for Children'. *Journal of Medical Ethics* 41 (3): 158–63. https://www.academia.edu/19117334/In_defense_of_genital_autonomy_for_children.
- Earp, Brian D. 2016. 'Between Moral Relativism and Moral Hypocrisy: Reframing the Debate on "FGM"'. *Kennedy Institute of Ethics Journal*.
- Earp, Brian D, Jennifer Hendry, and Michael Thomson. 2017. 'Reason and Paradox in Medical and Family Law: Shaping Children's Bodies'. *Medical Law Review* 25 (4): 604–27. <https://doi.org/10.1093/medlaw/fwx027>.
- Earp, Brian D., and Rebecca Steinfeld. 2018. 'Genital Autonomy and Sexual Wellbeing'. *Current Sexual Health Reports*, January. https://www.researchgate.net/publication/322807486_Genital_autonomy_and_sexual_wellbeing.
- Earp, Brian, and Rebecca Steinfeld. 2017. 'Gender and Genital Cutting: A New Paradigm'. *EuroMind* (blog). 6 April 2017. <http://euromind.global/en/brian-d-earp-and-rebecca-steinfeld/>.
- Edgerton, Milton. 1993. 'Discussion: Clitoroplasty for Clitoromegaly Due to Adrenogenital Syndrome Without Loss of Sensitivity'. *Plastic & Reconstructive Surgery* 91 (5): 956.
- Ellens, Rebecca E.H., Dana M. Bakula, Alexandria J. Mullins, Kristy J. Scott Reyes, Paul Austin, Laurence Baskin, Kerly Bernabé, et al. 2017. 'Psychological Adjustment of Parents of Children Born with Atypical Genitalia 1 Year after Genitoplasty'. *The Journal of Urology* 198 (4): 914–20. <https://doi.org/10.1016/j.juro.2017.05.035>.
- Family Court of Australia. 1979. In the marriage of C and D (falsely called C). Family Court of Australia.
- . 2009. Re Lesley (Special Medical Procedure). FamCA.
- . 2016. Re: Carla (Medical procedure). FamCA.

- . 2017. Re: Kaitlin. FamCA.
- Finlay, Henry A. 1980. 'Sexual Identity and the Law of Nullity'. *Australian Law Journal* 54 (3): 115–26.
- Frader J, Alderson P, Asch A, and et al. 2004. 'Health Care Professionals and Intersex Conditions'. *Archives of Pediatrics & Adolescent Medicine* 158 (5): 426–28. <https://doi.org/10.1001/archpedi.158.5.426>.
- Fraser, Kenneth, M. J. J. O'Reilly, and J. R. Rintoul. 1966. 'Hermaphroditus Verus, with Report of a Case'. *Medical Journal of Australia* 1 (24): 1003–8.
- Fricke, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.
- Fry, Rae. 2002. 'Boy or Girl?' *Radio National*, 25 February 2002. <http://www.abc.net.au/rn/talks/8.30/helthrtpt/stories/s490535.htm>.
- Gallagher, Katy. 2014a. 'Re the Commonwealth Senate Report on Involuntary or Coerced Sterilisation', 21 January 2014.
- . 2014b. 'Re the Births, Deaths and Marriages Registration Amendment Bill', 15 April 2014.
- Gillam, Lynn H., Jacqueline K. Hewitt, and Garry L. Warne. 2010. 'Ethical Principles for the Management of Infants with Disorders of Sex Development'. *Hormone Research in Paediatrics* 74 (6): 412–18. <https://doi.org/10.1159/000316940>.
- . 2011. 'Ethical Principles: An Essential Part of the Process in Disorders of Sex Development Care'. *Hormone Research in Paediatrics* 76 (5): 367–68. <https://doi.org/10.1159/000328316>.
- González, Ricardo, and Barbara M. Ludwikowski. 2016. 'Should CAH in Females Be Classified as DSD?' *Frontiers in Pediatrics* 4 (May). <https://doi.org/10.3389/fped.2016.00048>.
- Graves, Jenny. 2016. 'Boy, Girl or ...? Dilemmas When Sex Development Goes Awry'. *The Conversation*, 11 March 2016. <http://theconversation.com/boy-girl-or-dilemmas-when-sex-development-goes-awry-49359>.
- Greenberg, Julie A. 2012. *Intersexuality and the Law: Why Sex Matters*. New York: New York University Press.
- Greenhalgh, Trish. 2018. 'The Cochrane Collaboration—What Crisis?' *The BMJ* (blog). 17 September 2018. <https://blogs.bmj.com/bmj/2018/09/17/trish-greenhalgh-the-cochrane-collaboration-what-crisis/>.
- Hendricks, Melissa. 1993. 'Is It a Boy or a Girl?' *Johns Hopkins Magazine* 45 (6): 10–16.
- Hewitt, Jacqueline K., and Garry L. Warne. 2009. 'Management of Disorders of Sex Development'. *Pediatric Health* 3 (1): 51–65. <http://dx.doi.org.ezproxy1.library.usyd.edu.au/10.2217/17455111.3.1.51>.
- Hoffmann, Tammy C., and Chris Del Mar. 2017. 'Clinicians' Expectations of the Benefits and Harms of Treatments, Screening, and Tests: A Systematic Review'. *JAMA Internal Medicine* 177 (3): 407–19. <https://doi.org/10.1001/jamainternmed.2016.8254>.
- Holmes, Morgan. n.d. 'Is Growing up in Silence Better Than Growing up Different?' Intersex Society of North America. Accessed 30 December 2013. <http://www.isna.org/node/743>.
- Houk, C. P., I. A. Hughes, S. F. Ahmed, P. A. Lee, and Writing Committee for the International Intersex Consensus Conference Participants. 2006. 'Summary of Consensus Statement on Intersex Disorders and Their Management'. *PEDIATRICS* 118 (2): 753–57. <https://doi.org/10.1542/peds.2006-0737>.

- Hughes, I A, C Houk, S F Ahmed, P A Lee, and LWPES/ESPE Consensus Group. 2006. 'Consensus Statement on Management of Intersex Disorders'. *Archives of Disease in Childhood* 91 (April): 554–63. <https://doi.org/10.1136/adc.2006.098319>.
- Human Rights Commission, and New Zealand. 2018. 'Intersex Roundtable Report 2017 Ending the Practice of Genital Normalisation on Intersex Children in Aotearoa New Zealand'.
- Human Rights Commission of the City and County of San Francisco, and Marcus de María Arana. 2005. *A Human Rights Investigation Into The Medical "Normalization" Of Intersex People*. San Francisco.
- Human Rights Committee. 2017. 'Concluding Observations on the Sixth Periodic Report of Australia'. CCPR/C/AUS/CO/6.
- Human Rights Watch. 2017. "I Want to Be Like Nature Made Me". <https://www.hrw.org/report/2017/07/25/i-want-be-nature-made-me/medically-unnecessary-surgeries-intersex-children-us>.
- International Association of Athletics Federations. 2018. 'Eligibility Regulations for Female Classification (Athletes with Differences of Sexual Development)'. IAAF.
- Intersex Human Rights Australia. 2012. 'Including Intersex People in Forms, Studies and Surveys'. <https://ihra.org.au/forms/>.
- . 2016. 'Demographics'. <https://ihra.org.au/demographics/>.
- . 2018a. 'Submission to the Australian Law Reform Commission on the Review of the Family Law System – Issues Paper'. <https://ihra.org.au/32111/alrc-may-submission/>.
- . 2018b. 'CEDAW Shadow Report on Australia'. <https://ihra.org.au/32166/shadow-report-submission-cedaw/>.
- Jacobs, Rachael, and Denise Abou Hamad. 2017. 'Why Western Sydney Voted "No" To Marriage Equality'. *Huffington Post*, 20 November 2017, sec. Politics. https://www.huffingtonpost.com.au/rachael-jacobs/why-western-sydney-voted-no-to-marriage-equality_a_23282377/.
- Johnson, Emilie K., Iliina Rosoklija, Courtney Finlayson, Diane Chen, Elizabeth B. Yerkes, Mary Beth Madonna, Jane L. Holl, Arlene B. Baratz, Georgiann Davis, and Earl Y. Cheng. 2017. 'Attitudes towards "Disorders of Sex Development" Nomenclature among Affected Individuals'. *Journal of Pediatric Urology*, May. <https://doi.org/10.1016/j.jpuro.2017.03.035>.
- Jones, Melinda. 2017. 'Intersex Genital Mutilation – A Western Version of FGM'. *The International Journal of Children's Rights* 25 (2): 396–411. <https://doi.org/10.1163/15718182-02502008>.
- Jones, Tiffany. 2015. 'Intersex Study: Preliminary Demographics and Wellbeing Data'. presented at the Androgen Insensitivity Syndrome Support Group Australia annual conference, Brisbane, Australia, August 8.
- . 2016. 'The Needs of Students with Intersex Variations'. *Sex Education* 16 (6): 602–18. <https://doi.org/10.1080/14681811.2016.1149808>.
- . 2017. 'Intersex and Families: Supporting Family Members with Intersex Variations'. *Journal of Family Strengths* 17 (2). <http://digitalcommons.library.tmc.edu/jfs/vol17/iss2/8>.
- Karkazis, Katrina. 2008. *Fixing Sex: Intersex, Medical Authority, and Lived Experience*. Duke University Press.

- Karkazis, Katrina, and Morgan Carpenter. 2018. 'Impossible "Choices": The Inherent Harms of Regulating Women's Testosterone in Sport'. *Journal of Bioethical Inquiry*, August. <https://doi.org/10.1007/s11673-018-9876-3>.
- Karkazis, Katrina, and Rebecca M. Jordan-Young. 2018. 'The Powers of Testosterone: Obscuring Race and Regional Bias in the Regulation of Women Athletes'. *Feminist Formations* 30 (2): 1–39. <https://doi.org/10.1353/ff.2018.0017>.
- Kelly, Fiona, and Malcolm K Smith. 2017. 'Should Court Authorisation Be Required for Surgery on Intersex Children? A Critique of the Family Court Decision in Re Carla — (2017) 31 AJFL 118'. *Australian Journal of Family Law* 31 (2): 118–33.
- Kennedy, Aileen. 2009. 'Mutilation and Beautification'. *Australian Feminist Studies* 24 (60): 211–31. <https://doi.org/10.1080/08164640902852423>.
- . 2016. 'Fixed at Birth: Medical and Legal Erasures of Intersex Variations'. *UNSW Law Journal* 39 (2): 813–42. <http://www.unswlawjournal.unsw.edu.au/sites/default/files/392-14.pdf>.
- Kenya National Commission on Human Rights. 2018. *Equal in Dignity and Rights: Promoting The Rights of Intersex Persons In Kenya*. Nairobi: Kenya National Commission on Human Rights. <http://www.knchr.org/Publications/Thematic-Reports/Group-Rights/Rights-of-Sexual-Minorities>.
- Kerridge, Ian, Michael Lowe, and Cameron Stewart. 2013. 'Chapter 22: Children'. In *Ethics and Law for the Health Professions*, Fourth edition, 582–604. Annandale, NSW: The Federation Press.
- Kirkland, Faye. 2017. 'Intersex Patients "Routinely Lied to by Doctors"'. *BBC News*, 22 May 2017, sec. Health. <http://www.bbc.com/news/health-39979186>.
- Klöppel, Ulrike. 2016. 'Zur Aktualität kosmetischer Operationen „uneindeutiger“ Genitalien im Kindesalter'. *Gender Bulletin*, no. 42 (December). https://www.gender.huberlin.de/de/publikationen/gender-bulletins/texte-42/kloeppel-2016_zur-aktualitaet-kosmetischer-genitaloperationen.
- Kuhnle, Ursula, and Wolfgang Krahl. 2002. 'The Impact of Culture on Sex Assignment and Gender Development in Intersex Patients'. *Perspectives in Biology and Medicine* 45 (1): 85–103. <https://doi.org/10.1353/pbm.2002.0011>.
- Lambda Legal, and interACT. 2018. 'Intersex-Affirming Hospital Policies'. https://www.lambdalegal.org/sites/default/files/publications/downloads/resource_20180719_hospital-policies-intersex.pdf.
- Lee, Peter A., Anna Nordenström, Christopher P. Houk, S. Faisal Ahmed, Richard Auchus, Arlene Baratz, Katharine Baratz Dalke, et al. 2016. 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care'. *Hormone Research in Paediatrics* 85 (3): 158–180. <https://doi.org/10.1159/000442975>.
- Liao, Lih-Mei, and Margaret Simmonds. 2013. 'A Values-Driven and Evidence-Based Health Care Psychology for Diverse Sex Development'. *Psychology & Sexuality* 5 (1): 83–101. <https://doi.org/10.1080/19419899.2013.831217>.
- Liao, Lih-Mei, Dan Wood, and Sarah M Creighton. 2015. 'Parental Choice on Normalising Cosmetic Genital Surgery'. *BMJ* 351 (September): h5124. <https://doi.org/10.1136/bmj.h5124>.
- Liao, L.M. 2003. 'Learning to Assist Women Born with Atypical Genitalia: Journey through Ignorance, Taboo and Dilemma'. *Journal of Reproductive and Infant Psychology* 21 (3): 229–38. <https://doi.org/10.1080/0264683031000154971>.

- Littlefield, Amy. 2018. 'Intersex People Want to End Nonconsensual Surgeries. A California Resolution Is Their "Warning Shot."' *Rewire.News*, 13 August 2018. <https://rewire.news/article/2018/08/13/intersex-people-want-to-end-nonconsensual-surgeries-a-california-resolution-is-their-warning-shot/>.
- Lohman, Stephani, Eric Lohman, and Georgiann Davis. 2018. *Raising Rosie Our Story of Parenting an Intersex Child*. London: Jessica Kingsley Publishers. <http://public.eblib.com/choice/PublicFullRecord.aspx?p=5435797>.
- Malta. 2018. *Gender Identity, Gender Expression and Sex Characteristics Act*. <http://www.justiceservices.gov.mt/DownloadDocument.aspx?app=lom&itemid=12312&l=1>.
- Meyer-Bahlburg, Heino. 2005. 'Intersex: Fact or Fiction? Intersex and Identity. The Contested Self by Sharon E Preves'. *The Journal of Sex Research* 42 (2): 177–80. <http://www.jstor.org/stable/3813156>.
- Monro, Surya, Daniela Crocetti, Tray Yeadon-Lee, Fae Garland, and Mitch Travis. 2017. 'Intersex, Variations of Sex Characteristics, and DSD: The Need for Change'. Monograph. <http://eprints.hud.ac.uk/id/eprint/33535/>.
- Morland, Iain. 2011. 'Intersex Treatment and the Promise of Trauma'. In *Gender and the Science of Difference Cultural Politics of Contemporary Science and Medicine*, edited by Jill Fisher. New Brunswick, New Jersey: Rutgers University Press. <http://rutgerspress.rutgers.edu/product/Gender-and-the-Science-of-Difference,4038.aspx>.
- Mouratin, Pedro, and Instituto Nacional contra la Discriminación, la Xenofobia y el Racismo. 2015. *Documento temático INADI: Intersexualidad*. Ciudad Autónoma de Buenos Aires: Instituto Nacional contra la Discriminación, la Xenofobia y el Racismo - INADI. <http://inadi.gob.ar/wp-content/uploads/2015/07/intersexualidad.pdf>.
- National Foundation for Australian Women, and The University of Melbourne. 2016. 'Wallbank, Rachael - Woman - The Australian Women's Register'. Document. 18 November 2016. <http://www.womenaustralia.info/biogs/AWE5634b.htm>.
- Nokoff, N.J., B. Palmer, A.J. Mullins, C.E. Aston, P. Austin, L. Baskin, K. Bernabé, et al. 2017. 'Prospective Assessment of Cosmesis before and after Genital Surgery'. *Journal of Pediatric Urology* 13 (1): 28.e1-28.e6. <https://doi.org/10.1016/j.jpuro.2016.08.017>.
- O'Connor, Denise, Ian Harris, and Rachelle Buchbinder. 2018. 'Needless Procedures: Knee Arthroscopy Is One of the Most Common but Least Effective Surgeries'. *The Conversation*, 13 September 2018. <http://theconversation.com/needless-procedures-knee-arthroscopy-is-one-of-the-most-common-but-least-effective-surgeries-102705>.
- O'Connor, Mike. 2016. 'The Treatment of Intersex and the Problem of Delay: The Australian Senate Inquiry into Intersex Surgery and Conflicting Human Rights for Children'. *Journal of Law and Medicine* 23 (3): 531–43.
- O'Dwyer, Skye. 2017. "'Treatment" of Intersex Children as a Special Medical Procedure'. *Journal of Law and Medicine* 24: 870–85.
- Office of the High Commissioner for Human Rights, African Commission on Human and Peoples' Rights, Council of Europe, Office of the Commissioner for Human Rights, Inter-American Commission on Human Rights, Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Special Rapporteur on violence against women, its causes and

- consequences, and Special Representative of the UN Secretary-General on Violence against Children. 2016. 'Intersex Awareness Day – Wednesday 26 October. End Violence and Harmful Medical Practices on Intersex Children and Adults, UN and Regional Experts Urge'. Office of the High Commissioner for Human Rights. <http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&LangID=E>.
- Office of the Privacy Commissioner. 2018. 'Handling Health Information of Intersex Individuals'. *Office of the Privacy Commissioner* (blog). 2 March 2018. <https://www.privacy.org.nz/blog/handling-health-information-of-intersex-individuals/>.
- Orentlicher, Diane, and Economic and Social Council. 2005. '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'. E/CN.4/2005/102/Add.1. UN Commission on Human Rights.
- Organisation Intersex International Australia. 2017. 'Gaslighting in Victoria'. OII Australia - Intersex Australia. 18 May 2017. <https://oii.org.au/31391/gaslighting-in-victoria/>.
- Parliament of Queensland. 2008. 'Health Legislation (Restriction on Use of Cosmetic Surgery for Children and Another Measure) Amendment Bill 2008 Explanatory Notes'. <https://www.legislation.qld.gov.au/view/pdf/bill.first.exp/bill-2008-1380>.
- People with Disability Australia. 2018. 'Social Model of Disability'. 2018. <https://pwd.org.au/resources/social-model-of-disability/>.
- Queensland Health. 2016. 'Queensland Sexual Health Strategy'. Text QH845 11/16. <https://www.health.qld.gov.au/public-health/topics/sexual-health/strategy>.
- Reis, Elizabeth. 2012. *Bodies in Doubt: An American History of Intersex*. Baltimore: Johns Hopkins University Press.
- Reitsma, Welmoed, Marian J.E. Mourits, Merel Koning, Astrid Pascal, and Berend van der Lei. 2011. '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* 8 (8): 2377–85. <https://doi.org/10.1111/j.1743-6109.2011.02321.x>.
- Richards, Bernadette, and Thaddeus Mason Pope. 2017. 'Stretching the Boundaries of Parental Responsibility and New Legal Guidelines for Determination of Brain Death'. *Journal of Bioethical Inquiry*, August. <https://doi.org/10.1007/s11673-017-9803-z>.
- Royal Children's Hospital Melbourne. 2013. 'Submission of the Royal Children's Hospital Melbourne 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'. Royal Children's Hospital Melbourne. <http://www.aph.gov.au/DocumentStore.ashx?id=84e279b0-e824-4d4a-9aba-080b11077117&subId=16195>.
- Sandberg, David. 1995. 'A Call for Clinical Research'. In *Hermaphrodites With Attitude*, 8–9. <http://www.isna.org/files/hwa/winter1996.pdf>.
- Sandberg, Kirsten. 2015. 'The Rights of LGBTI Children under the Convention on the Rights of the Child'. *Nordic Journal of Human Rights* 33 (4): 337–52. <https://doi.org/10.1080/18918131.2015.1128701>.
- . 2018. 'Intersex Children and the UN Convention on the Rights of the Child'. In *The Legal Status of Intersex Persons*, edited by Jens Scherpe, Anatol Dutta, and Tobias

- Helms, 515–48. Cambridge, England: Intersentia. <http://intersentia.com/en/the-legal-status-of-intersex-persons.html>.
- Schneuer, Francisco J, Jason P Bentley, Andrew J Davidson, Andrew JA Holland, Nadia Badawi, Andrew J Martin, Justin Skowno, Samantha J Lain, and Natasha Nassar. 2018. 'The Impact of General Anesthesia on Child Development and School Performance: A Population-Based Study'. *Pediatric Anesthesia*, April. <https://doi.org/10.1111/pan.13390>.
- Schneuer, Francisco J., Jason P. Bentley, Andrew J.A. Holland, Samantha J. Lain, Sarra E. Jamieson, Nadia Badawi, and Natasha Nassar. 2017. 'Early Childhood Development of Boys with Genital Anomalies: Childhood Development of Boys with Genital Anomalies'. *Birth Defects Research* 109 (8): 535–42. <https://doi.org/10.1002/bdra.23603>.
- Shahvisi, Arianne, and Brian D Earp. 2018. 'The Law and Ethics of Female Genital Cutting'. In *Female Genital Cosmetic Surgery: Interdisciplinary Analysis & Solution*, edited by S Creighton and L-M Liao. Cambridge, England: Cambridge University Press.
- Shawky, Rabah M., and Sahar M. Nour El-Din. 2012. 'Profile of Disorders of Sexual Differentiation in the Northeast Region of Cairo, Egypt'. *Egyptian Journal of Medical Human Genetics* 13 (2): 197–205. <https://doi.org/10.1016/j.ejmhg.2012.03.003>.
- Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment. 2013. 'Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment'. A.HRC.22.53.
- Spriggs, Merle. 2016. 'Parent-Led Request for Female Genital Cosmetic Surgery in an Adolescent'. In *When Doctors and Parents Disagree: Ethics, Paediatrics and the Zone of Parental Discretion*, edited by Rosalind McDougall, Clare Delany, and Lynn Gillam, 227–43. Annandale, NSW: Federation Press.
- Spriggs, Merle, and Lynn Gillam. 2016. 'Body Dysmorphic Disorder: Contraindication or Ethical Justification for Female Genital Cosmetic Surgery in Adolescents: Body Dysmorphic Disorder'. *Bioethics* 30 (9): 706–13. <https://doi.org/10.1111/bioe.12278>.
- Streuli, Jürg C., Effy Vayena, Yvonne Cavicchia-Balmer, and Johannes Huber. 2013. '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* 10 (8): 1953–60. <https://doi.org/10.1111/jsm.12214>.
- Svoboda, J. Steven. 2013. 'Promoting Genital Autonomy by Exploring Commonalities between Male, Female, Intersex, and Cosmetic Female Genital Cutting'. *Global Discourse* 3 (2): 237–55. <https://doi.org/10.1080/23269995.2013.804757>.
- Sydney Children's Hospital at Westmead, Sydney Children's Hospital, Randwick, and Kaleidoscope Children, Young People and Families. 2015. 'Male Infant Circumcision'. http://www.schn.health.nsw.gov.au/files/factsheets/male_infant_circumcision-en.pdf.
- The Royal Australian and New Zealand College of Psychiatrists. 2018. 'Submission to the Australian Law Reform Commission on the Review of the Family Law System – Issues Paper'.
- Third international intersex forum. 2013. 'Malta Declaration: Public Statement by the Third International Intersex Forum'. Floriana, Malta. <https://ihra.org.au/24241/public-statement-by-the-third-international-intersex-forum/>.

- Topsfield, Jewel. 2018. 'Inquiry into Human Rights of Intersex People'. *The Sydney Morning Herald*, 15 September 2018. <https://www.smh.com.au/politics/federal/inquiry-into-human-rights-of-intersex-people-20180915-p503xg.html>.
- United Nations. 1984. 'Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment'.
<http://www.ohchr.org/Documents/ProfessionalInterest/cat.pdf>.
- . 2006. 'Convention on the Rights of Persons with Disabilities'. Geneva: United Nations. <http://www.un.org/disabilities/convention/conventionfull.shtml>.
- United Nations High Commissioner for Human Rights. 2015. 'Opening Remarks by Zeid Ra'ad Al Hussein, United Nations High Commissioner for Human Rights at the Expert Meeting on Ending Human Rights Violations against Intersex Persons'.
<http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16431&LangID=E>.
- University of Glasgow. 2018. '7th I-DSD Symposium Programme. July 2019, São Paulo, Brazil.' https://www.gla.ac.uk/media/media_600530_en.pdf.
- Wallbank, Rachael. 2015. 'The Legal Status of People Who Experience Difference in Sexual Formation and Gender Expression in Australia'. In *The Legal Status of Transsexual and Transgender Persons*, edited by Jens M. Scherpe, 457–526. Cambridge, United Kingdom: Intersentia.
- Wang, Lily C., and Dix P. Poppas. 2017. 'Surgical Outcomes and Complications of Reconstructive Surgery in the Female Congenital Adrenal Hyperplasia Patient: What Every Endocrinologist Should Know'. *The Journal of Steroid Biochemistry and Molecular Biology*, Genetic Steroid Disorders, 165 (January): 137–44.
<https://doi.org/10.1016/j.jsbmb.2016.03.021>.
- Warne, Garry, and Jacqueline Hewitt. 2009. 'Disorders of Sex Development: Current Understanding and Continuing Controversy'. *Medical Journal of Australia* 190 (11): 612–13. [https://doi.org/190\(11\):612-613](https://doi.org/190(11):612-613).
- World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance. 2001. 'Durban Declaration and Programme of Action'.
- World Health Organization. 2018a. '46,XY Disorder of Sex Development Due to 5-Alpha-Reductase 2 Deficiency'. In *ICD-11 Foundation*.
<https://icd.who.int/dev11/f/en#/http%3a%2f%2fid.who.int%2fcd%2fentfity%2f1028755501>.
- . 2018b. '46,XY Disorder of Sex Development Due to 17-Beta-Hydroxysteroid Dehydrogenase 3 Deficiency'. In *ICD-11 Foundation*.
<https://icd.who.int/dev11/f/en#/http%3a%2f%2fid.who.int%2fcd%2fentfity%2f887793448>.
- World Health Organization, Office of the High Commissioner for Human Rights, UNAIDS, UNDP, UNECA, UNESCO, UNFPA, UNHCR, and UNIFEM, eds. 2008. *Eliminating Female Genital Mutilation: An Interagency Statement*. Geneva: World Health Organization.
http://www.un.org/womenwatch/daw/csw/csw52/statements_missions/Interagency_Statement_on_Eliminating_FGM.pdf.
- World Professional Association for Transgender Health. 2018. 'Committees'. 2018.
<https://www.wpath.org/about/committees>.

- Wünsch, L. 2012. 'Checklist for the Structural Description of the Deep Phenotype in Disorders of Sexual Development'. *International Journal of Endocrinology* 2012: 1–5. <https://doi.org/10.1155/2012/816365>.
- Yang, Jennifer, Diane Felsen, and Dix P. Poppas. 2007. 'Nerve Sparing Ventral Clitoroplasty: Analysis of Clitoral Sensitivity and Viability'. *The Journal of Urology* 178 (4): 1598–1601. <https://doi.org/10.1016/j.juro.2007.05.097>.
- Yogyakarta Principles. 2007. *The Yogyakarta Principles. Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity*.
- . 2017. *The Yogyakarta Principles Plus 10: Additional Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics, to Complement the Yogyakarta Principles*. <http://www.yogyakartaprinciples.org/principles-en/yp10/>.
- Zillén, Kavot, Jameson Garland, and Santa Slokenberga. 2017. 'The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties'. Committee on Bioethics of the Council of Europe.