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**Submission on the ACT government discussion paper on 'Key issues in the prohibition of deferrable medical interventions on intersex children'**

Submitted by Intersex Human Rights Australia (IHRA)

Endorsed by Intersex Peer Support Australia (IPSA) and the Intersex Trust Aotearoa New Zealand (ITANZ)



# 1 Contents

1	Contents.....	2
2	About this submission.....	4
3	About IHRA, IPSA and ITANZ.....	4
4	General principles and recommendations.....	5
4.1	Principles, norms and oversight.....	5
4.2	Inclusions and exclusions.....	6
4.3	Penalties and redress.....	6
4.4	Support for affirmative healthcare pathways to replace the existing medical model and eliminate gaps in clinical practice.....	6
5	Responses to questions in the discussion paper.....	7
5.1	What should be the objective(s) of intersex health care?.....	7
5.2	What should be the stated objective of any prohibition of deferrable medical interventions on intersex patients?.....	15
5.3	How should the objective of a prohibition be framed, so it is inclusive of both the rights of the child and the rights and responsibilities of parents and guardians to act in their children’s interests?.....	16
5.4	Should modification of sex characteristics be part of the criteria that define what is in scope of a prohibition?.....	18
5.5	If so, how should “sex characteristics” be defined?.....	19
5.6	Should a prohibition address gonadal surgery, other surgical and/or non-surgical medical interventions?.....	19
5.7	Should a definition of the scope of a prohibition refer to treatments that are deferable or irreversible, or should it use other concepts to define what treatments should be in scope? Why?.....	19
5.8	Should inclusion in scope depend on having a diagnosed variation in sex characteristics?.....	25
5.9	How should a definition be crafted to allow health professionals to undertake treatments that affect sex characteristics, but which are being undertaken for reasons unrelated to intersex status?.....	26
5.10	How should exceptions be described to allow clarity while avoiding overly wide interpretation of exceptions?.....	27
5.11	Should the regulation of medical interventions be based on a definition of “intersex” as a category of person, or should it be designed based on circumstances or principles?.....	28
5.12	If regulation of medical intervention should be based on intersex status, how should intersex be defined?.....	29

5.13	If a prohibition is based on circumstances (e.g. “alteration of sex characteristics”) or principles (e.g. “with the consent of the individual”), rather than limited to a category of people, how would such a definition affect cases not related to intersex status, such as male circumcision?.....	29
5.14	How can we best support the consent of a parent to make choices that preserve the consent of the child in a medical setting? .....	29
5.15	What if any procedural requirements should be met in order to consider that consent is freely given and fully informed? .....	30
5.16	What decision-making approaches could be effective in ensuring decision-makers, including parents, have sufficient support to make decisions that uphold children’s rights and best medical practice? .....	31
5.17	Should there be an independent or advisory body or person involved in intersex medical intervention decision-making? If an independent body or person plays a role to support decisions around medical interventions on intersex people: a) What should that be? b) How should it operate? c) What categories of decisions should be within its remit? 32	
6	References .....	33

## 2 About this submission

Thank you for publishing the discussion paper on 'Key issues in the prohibition of deferrable medical interventions on intersex children' (Chief Minister, Treasury and Economic Development Directorate 2020) and inviting feedback. We welcome the establishment of this process and the ability to comment on a possible framework for reforms in this area. This is a formal response by Intersex Human Rights Australia (IHRA), and endorsed by Intersex Peer Support Australia (IPSA) and the Intersex Trust Aotearoa New Zealand. It has been written by Morgan Carpenter, M.Bioeth (Sydney), M.InfTech (UTS), and co-executive director of IHRA. It has been supported through review and feedback by our boards of directors, and by community peer support people across our jurisdictions.

## 3 About IHRA, IPSA and ITANZ

**Intersex Human Rights Australia (IHRA)** is a national charitable organisation run by and for people born with intersex variations, formerly known as Organisation Intersex International (OII) Australia. We promote the health and human rights of people born with intersex variations, including rights to bodily autonomy and self-determination. Our goals are to help create a society where intersex bodies are not stigmatised, and where our rights as people are recognised. Since December 2016 we have been funded by foreign philanthropy to employ two part-time co-executive directors to engage in policy development and systemic advocacy work. We build community, evidence, capacity, and provide education and information resources. Our co-executive directors and other directors engage in work promoting consistent legislative and regulatory reform, reform to clinical practices, improvements to data collection and research. We also work to grow the intersex movement and the available pool of advocates and peer support workers, and address stigma, misconceptions and discrimination. Our work is conducted in line with a 2017 community-designed platform, the Darlington Statement, which sets out priorities for the intersex movement in our region (AIS Support Group Australia et al. 2017).

**Intersex Peer Support Australia (IPSA)**, also known as the AIS Support Group Australia, is an intersex peer support, information and advocacy group for people born with variations in sex characteristics and their families. IPSA tackles stigma and misconception surrounding intersex through education, and advocates on issues affecting the wider intersex community. We work towards improving affirmative healthcare, fostering intersex pride, strengthening our community and deepening social culture. IPSA is a peer-led, not-for-profit intersex organisation and a registered health promotion charity.

**Intersex Trust Aotearoa New Zealand (ITANZ)** is also a national charity. It was formed in 1997 and is run and led by people born with intersex variations. Like IHRA, ITANZ seeks to advance human rights, legal protections, peer support, education and training programs and documents as well as advocating for improved access to health care for intersex persons their whanau and loved ones. ITANZ members participated in the retreats that informed the Darlington Statement and we also use this document as a foundation for our advocacy work. The working relationship with our colleagues in Australia is close and based on a partnership model.

## 4 General principles and recommendations

Our submission is grounded in the following principles and papers:

- The Darlington Statement, a community consensus statement by individuals and organisations in Australia and Aotearoa/New Zealand, including IHRA and many members of our organisation (AIS Support Group Australia et al. 2017).
- The Yogyakarta Principles plus 10 (Yogyakarta Principles 2017). Co-executive director Morgan Carpenter was a member of the drafting committee and is a signatory of these Principles.
- Concluding observations to Australia by UN Treaty Bodies.
- Our submissions to the Australian Human Rights Commission and the Australian Law Reform Commission in 2018, which set out a series of responses to questions of oversight and other matters that are relevant to this discussion paper (Intersex Human Rights Australia 2018b, 2018c); our submission to the Australian Law Reform Commission was developed in consultation with disability law experts and Disabled People's Organisations Australia, and with thorough consideration of issues affecting transgender persons.

We recommend that a bill start with an expression of goals, values and principles, followed by the means to implement them:

### 4.1 Principles, norms and oversight

- Establish in law a human rights principle, through recognition of the right to bodily integrity, and the elimination of harmful practices – we present more detail on principles in response to question 2.
- Establish a general approach, through a prohibition of invasive or irreversible medical procedures that modify sex characteristics without an individual's free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm; this expression aims to address complexities in the meaning of 'medical necessity' and is drawn from the Yogyakarta Principles plus 10.
- Establish an oversight mechanism or body, identifying its membership and key aspects of how it is to operate, and how it should fulfil the human rights principles established in the bill. This is necessary to ensure transparency and accountability, and ensure the effectiveness of the proposed legislation, given that there are few relevant models of good practice and medical concepts are contested.
- Establish norms about provision of information to individuals and family members, based on the model provided by an Argentinian bill (Estévez 2020) and the Yogyakarta Principles plus 10 on the right to truth (Yogyakarta Principles 2017). The goal of this is to ensure non-coercive informed consent, and this should include provision of non-medicalised information and peer support (Streuli et al. 2013; Timmermans et al. 2018; Roen and Hegarty 2018).

## **4.2 Inclusions and exclusions**

- Identify specific types of intervention that are to be prohibited, such as interventions grounded in social and cultural norms and gender stereotypes, or ‘driven by social factors’ (Malta 2018); this might form a schedule to a bill.
- Identify existing jurisprudence that addresses female genital cutting (FGM), and how it will coexist with the bill.
- Identify specific types of intervention that are permitted or out of scope, such as ritual or routine male circumcision, providing the government and/or Assembly with an opportunity to amend the legislation to include these within scope.
- Identify urgent interventions where there is an evidenced high risk of gonadal tumours, or that are necessary to address salt wasting or inability to urinate, or temporarily block puberty; this might form a schedule to a bill.

## **4.3 Penalties and redress**

- Establish a criminal penalty for breaches of these provisions, as proposed by the Tasmanian Law Reform Institute (Tasmania Law Reform Institute 2020); this is not the subject of the issue paper but is necessary to make any reform effective.
- Establish a criminal penalty for jurisdiction shopping; this is not the subject of the issue paper but is necessary to make any reform effective, given the role of clinicians in other jurisdictions in treating children in the ACT.
- These penalties are justified by the harms inherent to harmful practices.
- Redress for those who have experienced harms in, or commenced in, the ACT (Peck and Feder 2017).

## **4.4 Support for affirmative healthcare pathways to replace the existing medical model and eliminate gaps in clinical practice**

- Establish a framework for resourced peer support and advocacy (systemic and individual advocacy) by intersex-led organisations including provision of psychological and social work support over the lifespan; this is necessary as a replacement for existing presumptions that surgery ‘fixes’ children with intersex variations.
- Provide for the collaborative development of standards of care – we discuss this briefly in our response to question 16.
- Provide for education about the existence of intersex people, with the goal of promoting awareness and reducing the potential for coercion in social and community settings.

We give detail to this proposed framework in our responses to the discussion paper questions, below. IHRA would welcome any opportunity to assist the ACT government further with the development and passage of such a bill.

We recommend that passage of a bill be accompanied by a formal and unambiguous apology for practices that exist to the present time.

## 5 Responses to questions in the discussion paper

### 5.1 What should be the objective(s) of intersex health care?

In our view, this question is fundamentally important as it can help to identify the values held by different stakeholders in relation to healthcare and people with intersex variations.

The issue paper cites nine objectives in healthcare, sourced from a 2016 global 'disorder of sex development' ('DSD') update:

*(1) minimising physical and psychosocial risk; (2) preserving potential for fertility; (3) upholding the individual's rights to participate in decisions that will affect their[sic] now or later; (4) leaving options open for the future by avoiding irreversible treatments that are not medically necessary until the individual has the capacity to consent; (5) providing psychosocial support and peer support; (6) supporting the individual's healthy sexual and gender identity development; (7) using a shared decision-making approach that respects the individual's and parents' wishes and beliefs; (8) respecting the family and parent child relationships, and (9) providing patients with full medical information appropriate for age, developmental stage and cognitive abilities (Lee et al. 2016).*

This set of principles is derived from a 2010 paper by clinicians in Victoria (Gillam, Hewitt, and Warne 2010). We comment on several of these principles below, notably the reference to 'psychosocial risks', supporting 'healthy sexual and gender identity development', and 'full medical information'. In response to later questions, we assert that parents' rights are not unfettered.

The principle of 'minimizing physical and psychosocial risk' combines two distinct and unrelated sets of risks: risks to physical health and 'psychosocial risks'. While some physical risks are uncontested, psychosocial risks and subjective views in relation to some physical risks are contentious. These assertions illustrate the subjectivity and role of fundamentally non-clinically relevant factors in making clinical decisions on grounds of psychosocial risks:

- *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 lives (Gillam, Hewitt, and Warne 2010, 415)*

When first published, these principles included a range of assertions about psychosocial risks including impaired marriage prospects, later cited in a Victorian guide to decision-making (see citation in Senate of Australia Community Affairs References Committee 2013,

para. 5.4). The 2010 paper was criticised by some clinicians at the time of publication. The paper was felt to be:

*responding to the major DSD debate of a decade ago, namely over genital surgeries in infancy...*

*The authors have opted to ignore the existing DSD ethics literature in an effort to arrive at principles putatively unburdened by previous ethical engagement... (Dreger, Sandberg, and Feder 2010)*

The inclusion of these principles in the global update reflects the clinically perceived benefits of a radical clean sweep that can unburden consciences and provide a veneer of objectivity, while justifying existing surgical practices in Victoria and elsewhere.

It is notable that the global update cites psychosocial rationales within the nine principles but also establishes that claims that surgery mitigates psychosocial risks lack evidence, clarifying that 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).

Current language in relation to psychosocial risks, in a 2020 book edited by Hutson, Grover and others nevertheless links concern about ‘reduced opportunities for marriage or intimate relationships’ to parental concerns ‘which lead them to prefer a particular sex of rearing’; this is a framing that curiously duplicates an additional (and longstanding) statement about the ‘possibility that a child will not be accepted by parents in the sex of rearing that would usually be recommended by doctors’ (Gillam 2020). Underlying these comments seems to be a discourse, more bluntly expressed in oral statements, where clinicians express views on the ethnicity of parents and an assumption that parents who belong to marginalised ethnicities will be less able to cope with particular forms of difference (see, for example, the discourse by Grover in J. Hutson, Grover, Delany, et al. 2020; and statements on culture, sexuality and gender roles in Vora and Srinivasan 2020). While unstated, this may refer to cultural preferences for boys; irrespective, such statements articulate a situation where different outcomes in relation to sex assignment and medical interventions arise in clinical settings, between children with the same characteristics but different ethnicity. This difference in outcome is a matter of concern, particularly given that sex assignment and medical interventions to reinforce sex of rearing have lifelong, irreversible consequences. Despite these racialised disparities in treatment, and in contrast to these notions that minoritised populations are at greater risk of expression of particular and distinct preferences that must be accommodated by clinicians, the current experience of some elite women athletes with intersex variations shows instead the adverse effects of western ideas of femininity on racialised bodies (Human Rights Watch 2020).

The 2016 global update also refers to a principle of ‘healthy sexual and gender identity development’. The underlying values behind this statement are not explicit, but Hegarty and others have commented about ‘projections of social norms onto children [which] inform the concept of “development”’ (Hegarty et al. 2020). We understand these to be heteronormative assumptions, reflecting gender stereotypes, which we discuss below.

The 2016 global update principles also refer specifically to the provision of ‘medical information’ which, while this might be regarded as maintaining a clinical focus on clinical information, is known to promote early surgical interventions (Streuli et al. 2013), and, as clinical spaces are the first and often only spaces made available for families and individuals to know about intersex, fail to create necessary room for additional perspectives. Additional perspectives are available within peer support and advocacy organisations, and from (underutilised) allied health professions such as psychology (Liao and Roen 2019; Hegarty et al. 2020). The principles make no mention of human rights norms engaged by medical practices.

Indeed, all nine principles obfuscate underlying values, such as the role of medicine in stigmatising vulnerable populations. These principles fail to account for the relationships of medicine, and of individuals and families, to their communities and society. They make implicit and unexamined assumptions about ‘normality’, about individual desire and wishes, and about the role of medicine. Nevertheless, the abstraction of rationales in summary statements like those in the global update of 2016 may be designed to disassociate current practices from their history and origins, convey an impression of objectivity, and facilitate ‘cargo culting’,<sup>1</sup> that is, the extraction and reproduction of the principles in other settings as if uncontentious and sufficient, without understanding the implications, and comprehending their purpose or history. Clinicians also invest in early surgeries while also professing the benefits of continued (and so future) technological advances (see, for example, J. Hutson, Grover, Delany, et al. 2020).

The discussion paper identifies a lack of consensus and a range of views within medicine in relation to concepts of normality, and determinations of ‘benefits’, ‘harms’ and ‘quality of life’. There is no consensus in medicine on a definition of ‘normal’, nor a definition of a ‘disease’, ‘illness’ or ‘disorder’. While the World Health Organization (WHO) has constructed a definition of ‘health’, this is also a definition that is contested and modified to taste. Given these disagreements, it is unsurprising that there is no clinical consensus on the objectives of intersex healthcare.

As an illustration, the discussion paper cites a claim made by Laurence Baskin that ‘medical guidance often includes a goal to make an intersex person as “normal” as possible’ (Baskin 2017). The author of the cited assertion, a prominent urological surgeon, is known for associating this concept of normality with a social conception of functionality, stating in a hearing of the Californian Senate in 2018:

*Our focus is to make sure that each person becomes a functional member of society ... 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).*

The author’s concept of ‘normal’ is clearly subjective; yet it also establishes that surgery is intended to result in a range of non-clinical, non-anatomical outcomes, perhaps related to

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<sup>1</sup> This term comes from software programming to describe an imitation of form without comprehension. It is also evident in the LGBT movement, where definitions of intersex may be included in an acronym or remit, but without addressing any implications of inclusion. For an explanation of the term see <https://blog.ndepend.com/cargo-cult-programming/>

ideas about reduced psychosocial risks and ‘healthy sexual and gender identity’, but reliant on implicit norms and stereotypes, and doing an exceptional amount of heavy lifting.

In 2016, Baskin co-authored a paper with Lee, Mouriquand, Poppas and others on ‘surgery in disorders of sex development (DSD) with a gender issue’, focusing on situations where there is ‘controversy’ about gender assignment. It replicates a number of arguments made in the contemporaneous global update (Lee et al. 2016), including noting little evidence regarding impact of treatment and non-treatment, and also an absence of consensus on indications, timing, procedure and evaluation of outcome of surgery, attributing this absence to ‘complexity and heterogeneity of presentation’ (Mouriquand et al. 2016). The authors state that the first two aims of surgery are:

- *Restore functional genital anatomy to allow future penetrative intercourse (as a male or a female),*
- *Facilitate future reproduction (as a male or a female) when possible,*

Other stated aims of surgery include:

- *Avoid late virilization at puberty in individuals raised as girls or breast development in individuals raised as boys,*
- *Foster development of “individual” and “social identities,”*
- *Avoid stigmatization related to atypical anatomy,*
- *To respond to the parents’ desire to bring up a child in the best possible conditions*

Each of these rationales for surgery appeals to heteronormative gender stereotypes, and a presumption that surgery can reduce or avoid stigma rather than exemplify it. The claim about reproductive capacity matches a principle in the 2016 global update on preserving potential fertility. These claims are notable as reproductive capacity only appears to matter where the type of reproductive capacity – gestation or insemination – is aligned with sex of rearing; the same implicit notion that bodies and identities should be made to align is also expressed in the notion that virilisation must be avoided in girls and feminine characteristics avoided in boys (surgery on the basis of these rationales can, of course, be avoided through use of puberty blockers). The final rationale listed above, on parental desires, is bluntly articulated by surgeon John Hutson in a debate with Morgan Carpenter in June 2020 (J. Hutson, Grover, Delany, et al. 2020). These rationales are also closely related to the principles drafted by Melbourne clinicians in 2010 (Gillam, Hewitt, and Warne 2010), quoted above, and substantively reproduced in the global update paper (Lee et al. 2016).

These issues, and in particular surgeons opining on psychosocial issues, likely inform aspects of the Californian Senate Bill 201 on information provision by physicians and surgeons (Wiener 2019, sec. 1 (f-g)).

Baskin and his fellow surgeons illustrate a series of arguments made in an influential 1951 paper, republished in 1987, by Talcott Parsons who states:

*the phenomena of physical and mental illness and their counteraction are more intimately connected with the general equilibrium of the social system than is generally supposed (Parsons 1951, 1987).*

Parsons describes illness:

*as a special type of what sociologists call “deviant” behavior. By this is meant behavior which is defined in sociological terms as failing in some way to fulfil the institutionally defined expectations of one of more of the roles in which the individual is implicated in the society [where] the therapeutic process must always have as one dimension the restoration of capacity to play social roles in a normal way (Parsons 1951, 1987).*

In turn, Parsons provides an illustration of what Irving Zola describes as the role of medicine as ‘a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law’ with an assumption that this process ‘leads to their removal from religious and legal scrutiny and thus from moral and punitive consequences’ (Zola 1972). Zola describes ‘the very privatized nature of medical practice, plus the continued emphasis that certain expert judgments must be free of public scrutiny’, and cites an example of a senior clinician arguing against provision of referrals to self-help groups (Zola 1972). Zola questions such assumptions, drawing upon examples including abortion and homosexuality, to assert that:

*By locating the source and treatment of problems in an individual, other levels of intervention are effectively closed. By the very acceptance of a specific behaviour as an ‘illness’ and the definition of illness as an undesirable state, the issue becomes not whether to deal with a particular problem, but how and when [...] the more principled, more perplexing, or even moral issue, of what freedom should an individual have over his or her own body is shunted aside (Zola 1972).*

Parsons first wrote at around the same time that John Money and others published first guidelines on ‘case management’ of children with intersex variations, recommending early surgery in line with sex of rearing (Hampson, Money, and Hampson 1956). Peter Conrad identifies how medicalisation ‘describes a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders’, where, citing Clarke et al., ‘a growth of medical jurisdiction is “one of the most potent transformations of the last half of the twentieth century”’ (Conrad 2007).

Health is sometimes framed in medicine as the absence of disease, and this is held to be a ‘value-free theoretical notion’: Christopher Boorse, for example, has critiqued ‘recurrent themes’ in definitions of health, asserting that ‘none by itself provides a necessary or sufficient condition for disease’, for example, ‘One easily supposes that healthy people are those who do not need medical treatment, unhealthy ones those who do’, with many commentators regarding the circular constituent concepts in this notion as self-evident (Boorse 1977). Hegarty, Prandelli and others describe an ‘illusion of explanatory depth’ in clinician explanations of medical necessity, ‘that relies on norms to an extent that is not always clear to those who voice the expertise’ (Hegarty et al. 2020). In this regard, it is our view that multiple authors and institutions may now, through a process of ‘cargo culting’,

simply cite the ethical principles – either those elaborated by Gillam and others in 2010, or the similar versions by Mouriquand and others or in the global update – without considering their implications. In the same manner, in 2014 the then Chief and Health Minister of the ACT, referred in a letter to Morgan Carpenter to the existence of international and national statements as if they represented a consensus on the treatment of infants with ‘a disorder of sex development’, with a:

*standard investigation and management process 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, psychology and psychiatry (Gallagher 2014).*

Boorse influentially defined elements of health as ‘biological function and statistical normality’ (Boorse 1977). This view reflects a belief that science itself is objective and value-free. According to this definition, intersex traits are disorders. This disordering is not unique: Boorse has found it necessary to rebut claims that homosexuality is abnormal because it implies reduced rates of reproduction, and has done so weakly, by reference to possible ‘kin-selection hypothesis’ aetiologies of homosexuality (Boorse 2014, 691). A reliance on a likely unprovable hypothesis is a weak foundation for determining whether or not a stigmatised population can be characterised as pathological. Boorse’s biomedical view fails to take account of social and cultural biases, and fails to consider the existence of a direct relationship between diagnosis and treatment.

Current medical protocols in relation to children with intersex variations developed in the 1950s, accompanied by particular social and cultural views about sex and normality (Hampson, Money, and Hampson 1956; Carpenter 2020b). While cultural and social attitudes towards sex and gender have shifted in many countries, intersex variations have since 2006 been framed in medicine as medical disorders that can be ‘fixed’ to improve health. Rationales are increasingly abstracted and renewed to disassociate them from past rationales, yet the core elements of medical practice remain the same. According to conventional theories about health, intersex people are inherently disordered. The rationale for this disordering is not always evident: some intersex variations are accompanied by particular health issues. However, ideas about what is disordered may rely on social and cultural norms, but also may be regarded as simply self-evident: a particular trait may be a disorder simply because clinicians regard it as a disorder, because it has a history as a disorder; that is, a trait is a disorder because it has been medicalised, and clinicians fix disorders because that is what clinicians do.

The disordering of intersex traits can be seen also in a failure to distinguish medical interventions due to medical necessity from medical interventions due to social and cultural norms. In the case of congenital adrenal hyperplasia (CAH), where salt wasting is possible and can be fatal if not treated, managing this risk requires regular medication, but it does not require genital surgery. Treating one aspect of CAH as a disorder does not require that another aspect of CAH also be treated as a disorder.

Failure to acknowledge connections between diagnosis and treatment creates assumptions that diagnosis requires treatment, and that treatment is effective, and can make someone ‘normal’. These views are prevalent in some medical literature in relation to CAH, which

demonstrate a belief in the success of early interventions in constructing cisgender, heterosexual (or at least fertile) women (Carpenter 2020b). Surgery, however, does not construct 'normal' bodies (Morland 2014). People with salt wasting CAH continue to need medical treatment; people subjected to early vaginoplasties have a high risk of stenosis, and possible urinary issues; surgery creates scarring and insensitivity.

The inability of surgery to create 'normal' bodies is particularly evident in literature on hypospadias. Clinicians at RCH Melbourne have asserted that there is evidence of better psychosocial outcomes in boys following early surgery when compared against later interventions where children remember the surgery (for example, see J. Hutson, Grover, O'Connell, et al. 2020, 239). A deliberate pre-empting of ability to consent to surgery, which is implied in undertaking surgery before an individual can consent, has been identified as a human rights violation (Office of the High Commissioner for Human Rights 2019). Setting this violation aside for a moment to consider the remaining rationale, the hospital's assertions are based on two studies. The first is a single small study of patients by their clinicians at a single institution that show significant 'negative genital appraisals' and greater inhibitions and embarrassment than controls, but also a correlation between age of surgery and extent of sexual inhibition (Mureau, Slijper, van der Meulen, et al. 1995). The second is a smaller study by clinicians at RCH Melbourne of their patient children reviewed at ages 13-15 'An association was found between no recollection of surgery and satisfaction with body appearance' (B. Jones et al. 2009). The RCH study was conducted by clinicians of their own patients, creating risks of confirmation and ascertainment bias, and had a low response rate. This discussion is relevant to consideration of concepts of 'normality' as Mureau and others report on a 'norm-related' study of 'psychosexual and psychosocial adjustment' of patients. A third of respondents subjected to hypospadias surgery reported inhibitions in 'seeking sexual contacts' due to genital appearance, 84.7% considered their genital appearance to be 'different from that of other men', and 37% desired improved functionality or appearance (Mureau, Slijper, van der Meulen, et al. 1995). In a second publication that same year, the authors write that goals of surgery are to enable urination while standing, 'unhampered' insemination, and 'achievement of a cosmetic appearance of the penis that is as "normal" as possible', yet:

*Boys who have been told that their penis will be "normal" after surgery could be very disappointed with the cosmetic result (Mureau, Slijper, Slob, et al. 1995)*

In addition, urethral strictures (narrowing) and other complications may occur many decades after early surgeries (Barbagli et al. 2012) and have been described as a 'natural evolution' of hypospadias repair (Barbagli 2010), perhaps being a 'normal' outcome, while sexual pleasure and sensation is not a clinical priority in surgeries that can involve 'resurfacing' the penis. In contrast with these studies of children with hypospadias, a 1995 study of 500 men found that only 55% were 'normal' with no indication of hypospadias (Fichtner et al. 1995).

While illustrating a lack of consensus about 'normal', and an inability of medicine to construct 'normal' appearance, these issues might lend weight to an analysis by Alice Dreger, citing George Canguilhem: that it is easier to identify something that doesn't conform, than identify the norm. As Dreger comments:

*Georges Canguilhem noted in his study of the normal and the pathological, "it is not paradoxical to say that the abnormal, while logically second, is existentially first." In other words, we tend to assume that the normal (in this case the "normal" sexual anatomy) existed before we encountered the abnormal, but it is really only when we are faced with something that we think is "abnormal" that we find ourselves struggling to articulate what "normal" is. (Dreger 2003, 35)*

In contrast to Boorse and Canguilhem, Ron Amundson asserts that 'normality is a biological error' where 'Diversity of function is a fact of biology':

*the doctrine of biological normality is itself one aspect of a social prejudice against certain functional modes or styles. The disadvantages experienced by people who are assessed as 'abnormal' derive not from biology, but from implicit social judgments about the acceptability of certain kinds of biological variation' (Amundson 2000, 33).*

Our approach is strongly informed by this perspective which is closely aligned with the social model of disability (People with Disability Australia 2018a): a model that, in contrast to a medical model that focuses on perceived individual deficits, draws attention to the role of socially constructed barriers.

Multiple marginalised and minoritised groups have different modes of being. Marginalised and minoritised groups (including women, Indigenous people and other racialised minorities, sexual and gender minorities, and people with disabilities) uncontroversially still suffer stigma and discrimination in medicine; many of these issues are presently evident in differential risks of adverse outcomes relating to COVID19, such as those affecting non-white healthcare workers or access by people with disabilities to intensive care services made scarce by prior political decisions. It should be no surprise that intersex health care is similarly encumbered.

Stigma and marginalisation can create social contexts where decisions are made due to coercion (Carpenter 2020c, 594), that is, where individuals are encouraged, educated or otherwise made to understand their body in particular ways that promote surgical or other medical 'solutions'. Jonathan Metzl and others call for clinicians to develop structural competency and structural humility – an awareness of upstream structural and social determinants of health, and even 'the very definitions of illness and health' – in order to address 'structural stigma at the center of conceptualizations of illness and health' (Metzl and Hansen 2014).

Health care, including intersex health care, should have the objectives:

- to respect and support diverse modes of being, including modes that are stigmatised or marginalised.
- to empower individuals to make their own informed choices about their needs, maximising opportunities for personal informed choice about irreversible or invasive non-urgent interventions.

- to challenge stigma and marginalisation, particularly within medicine. Health care workers in relevant fields should collaborate with community organisations and members to challenge stigmatisation and marginalisation through both specific clinical training and education in society more generally.
- that are entirely compatible with respect for the human rights of the child and of other individuals, including the elimination of harmful practices and recognition of the right to bodily integrity.
- to fund medical interventions when sought, irrespective of age (and removing this particular incentive for early surgery); facilitate access to experimental treatments where an individual provides informed consent about their own health care; and fund non-medical alternatives to medical interventions including peer support, and individual and systemic advocacy.

Expressions on elimination of harmful practices and recognition of the right to bodily integrity are drawn from statements by UN Treaty Bodies in concluding observations to Australia, in particular, the framework of ‘harmful practices’ is one that is used by the CRC and CEDAW (Committee on the Elimination of Discrimination against Women 2018; Committee on the Rights of the Child 2019).

## **5.2 What should be the stated objective of any prohibition of deferrable medical interventions on intersex patients?**

We note that the framing of this question, contrarily to a draft form of this question, in its reference to ‘intersex patients’ presupposes a need for medicalisation, and that presumption may be driven by normative ideas about bodies, function, and the role of medicine in constructing ‘normal’ social structures.

In line with the concluding observations of UN Treaty Bodies, stated objectives should be:

- to eliminate harmful practices (Committee on the Elimination of Discrimination against Women 2018; Committee on the Rights of the Child 2019).
- to recognise and implement the right to bodily integrity (Committee on the Rights of the Child 2019; see also, on ‘protecting the integrity of the person’, Committee on the Rights of Persons with Disabilities 2019).
- to ensure personal informed consent to medical interventions that modify an individual’s sex characteristics without strict medical necessity (Committee on the Rights of Persons with Disabilities 2019; Committee on the Rights of the Child 2019; Human Rights Committee 2017).
- to provide redress to individuals who have experienced forced and coercive medical interventions (Committee on the Elimination of Discrimination against Women 2018).
- to provide oversight of medical interventions where uncertainty about necessity or urgency exists, and ensure transparency and accountability of medical practitioners for the successful operation of the prohibition (see statements on implementing the recommendations of the 2013 Senate committee inquiry on the involuntary or

coerced sterilisation of intersex people by Human Rights Committee 2017; and by Committee on the Elimination of Discrimination against Women 2018).

- to ensure provision of independent, resourced, peer and family support (Committee on the Rights of the Child 2019; Committee on the Rights of Persons with Disabilities 2019; Committee on the Elimination of Discrimination against Women 2018).

Additionally, the objective of a prohibition should be to maximise personal informed choice about any irreversible or invasive, non-urgent medical interventions.

These positions are not striking or unusual – they affirm accepted human rights positions and accepted positions in common law regarding the right to consent to treatment.

Our focus on harmful practices is based on statements by UN Treaty Bodies, and the employment of that framework in concluding observations to Australia (Committee on the Elimination of Discrimination against Women 2018; Committee on the Rights of the Child 2019). We have previously recommended to Equality Australia to employ this framework in relation to forced and coercive medical practices on intersex people, and in relation to queer and trans conversion practices (Equality Australia 2019); this unambiguously positions these practices within a justice and human rights framework. The Capital of Equality First Action plan refers to these under the heading ‘keeping people safe from harm’ (ACT Government 2019). Harmful practices are prejudicial to health and wellbeing, grounded in gender stereotypes and norms, and reflect social and community beliefs (Committee on the Elimination of Discrimination against Women and Committee on the Rights of the Child 2014). States have an obligation to condemn harmful practices, ensure prompt, impartial and independent investigation, and ensure that legislation is consistent and comprehensive, accompanied by meaningful sanctions and redress; the involvement of medical professionals or government employees is an ‘aggravating circumstance’ (Committee on the Elimination of Discrimination against Women and Committee on the Rights of the Child 2014). In some cases, harmful practices can be distinguished from acceptable practices by referring to the age and consent of an individual (e.g. forced and child marriage).

### **5.3 How should the objective of a prohibition be framed, so it is inclusive of both the rights of the child and the rights and responsibilities of parents and guardians to act in their children’s interests?**

The interests (including the best interests and the right to bodily integrity) of children are paramount. These interests may differ from those of their parents, and parents do not have an unfettered right to make decisions on behalf of their children. The legislation should propose to eliminate harmful practices and protect the right of people with variations of sex characteristics to bodily integrity. These fundamental human rights principles take precedence over parental rights, in the same way that parental rights are overridden in relation to other harmful practices; parents are not entitled to consent to child marriage, body modifications for the purpose of beauty or marriageability of girls and women, or FGM. In relation to FGM, the UN OHCHR background note on human rights violations against intersex persons notes the role of parental motivations:

*The practice persists due to normative ideas about women's bodies, normative and unequal gender roles, and social control over women, including the harmful notions that women must undergo the ritual in order to be eligible for marriage or as a rite of passage to adulthood. In some cases, parents may be motivated to consent to female genital mutilation because they see other parents doing so; women subjected to the procedure may also exert pressures that promote conformity and ostracize others (Office of the High Commissioner for Human Rights 2019).*

In addition to an implementation of Australian model law on FGM, Queensland has introduced an explicit prohibition of certain forms of cosmetic surgery on children, via a list of specified procedures, including breast alterations, skin resurfacing and a range of other procedures. The legislated prohibition is enforced with a maximum penalty of '2000 penalty units or 2 years imprisonment', combined with an exemption for procedures 'in the best interests of the child', and specification of a broad range of concerns that can be used to evidence those interests; while those reference existence of a 'congenital abnormality or the physical effect of a medical condition' and 'the child's psychological health', and ability to defer a procedure until adulthood, the legislation provides a precedent for a prohibition of certain medical procedures on children other than those referring to FGM (Queensland 2008).

Generally, the law should protect the existing right that children and adolescents (and adults) have to bodily integrity, physical autonomy and self-determination. This right should be respected except where necessary to avoid serious, urgent and irreparable harm to the child or adolescent. In line with statements by the UN Committee on the Rights of the Child (Carpenter 2020b, 10), acting in children's best interests should not be 'manipulated to justify practices that conflict with the child's right to bodily integrity' (Yogyakarta Principles 2017, 10).

Parents should not be stigmatised because they follow current clinical advice. Liao, Wood and Creighton remark that:

*Parents may not realise that they are de facto opting for experimental surgery on their children. Furthermore, their emotional states during decision making may not be optimal. Research suggests that medicalised presentations of genital difference have undue influence on parental decisions and that parental regret can be high [...]*

*There is no evidence that parents are given sufficient time to appreciate their child, effective psychosocial support to manage their emotional reactions, or help to slowly digest the highly complex medical information and implications.*

*There is no identifiable psychoeducational care pathway to help parents deal with situations that may feel daunting (Liao, Wood, and Creighton 2015)*

Limiting parental rights should not happen in isolation, as parents and guardians require support to adjust to living with a child who is different (Hegarty et al. 2020; Parens 2008;

Lee et al. 2016; Liao, Wood, and Creighton 2015). A failure to address the issue of ‘what happens next’ is likely to create uncertainty, or even a backlash through perceptions that the only available treatment model has been eliminated. It is essential that parents have access to, and utilise, resourced, independent support and advocacy from individuals and families with similar lived experience, and procedures currently made available for infants, children and adolescents must be available across the lifespan, funded through the public system in the same way as early interventions. This is necessary to remove a rationale based on age and cost, where early interventions are publicly funded but adult procedures are not, thus promoting early procedures on grounds of access. Reparative treatments should also be available in the same way as publicly-funded treatments, and this is currently often not the case.

Indeed, the rationale behind peer support is to enable an affirmative process of understanding different ways of being, outside of the medical model, that then impact medical decision-making (Hart 2018, 2019; Lum 2019). Currently much of this population is invisible outside the medical system because of a lack of meaningful signposting to support and advocacy organisations by clinicians who manage information flows to parents and families. Meaningful signposting by clinicians is essential, but a shared commitment to a human rights framework is necessary to enable that. Inclusion of peer support and advocacy organisations within interdisciplinary or multidisciplinary teams in hospital settings is also necessary; in discussion with community members in Intersex Peer Support Australia (IPSA), this has been noted as having been requested by peer-led groups for decades.

Access and utilisation of peer support can address stigma and marginalisation, while intersex-led advocacy work should shift from systemic advocacy to individual and systemic advocacy work, modelled on the experience of the disability sector. While we recognise positive developments following the recruitment of an intersex support worker, it remains our view that existing services are primarily focused on the needs of trans, gender diverse and queer populations where the needs of intersex populations are subordinated to those interests and concepts. We recommend that the ACT government support and promote intersex-led organising.

#### **5.4 Should modification of sex characteristics be part of the criteria that define what is in scope of a prohibition?**

Yes. ‘Modification of sex characteristics’ is neutral terminology that does not depend on changeable or contested clinical terminology.

Please see the discussion on nomenclature in the IHRA submission to the Australian Human Rights Commission inquiry (Intersex Human Rights Australia 2018b, 18–28).

For the avoidance of doubt, we do not support arguments that frame invasive surgeries to genitalia, including vaginoplasties, removal of vaginal tissue, clitoral recessions and phalloplasties as reversible on the basis that further surgeries can alter genitals to give a different appearance. All surgeries impact sensation, and these can be expected to impact sexual sensation and function. All surgeries are also accompanied by financial costs and

health risks, and utilise scarce health resources. Surgeries on young children, aged under 48 months, are also now known to be associated with risks to cognitive development (Schneuer et al. 2018).

### **5.5 If so, how should “sex characteristics” be defined?**

IHRA supports the definition of ‘sex characteristics’ in the Yogyakarta Principles plus 10. The definition in the *Discrimination Act 2020* (ACT) reflects this model and is appropriate (Minister for Justice, Consumer Affairs and Road Safety 2020).

### **5.6 Should a prohibition address gonadal surgery, other surgical and/or non-surgical medical interventions?**

Yes. A contrary focus only on surgeries that affect reproductive organs and fertility would be an unduly narrow definition. Modifications to external genitalia (such as the phallus/penis/clitoris and labia), secondary sex characteristics (such as breasts) and hormonal interventions should be including within scope. The facts stated in the Family Court case *Re Kaitlin* show a need for prior informed consent by subjects of hormone treatment to commence puberty (Carpenter 2018b). Medical interventions have effects on a broad range of sex characteristics beyond those associated with reproductive organs and fertility, for example, hormonal treatments impact height.

A narrow prohibition would not address issues raised by the intersex movement regarding current and historic treatment protocols, and nor would such an approach address concerns raised by human rights institutions (Committee on the Elimination of Discrimination against Women 2018; Committee on the Rights of Persons with Disabilities 2019; Committee on the Rights of the Child 2019; Office of the High Commissioner for Human Rights 2019; Asia Pacific Forum of National Human Rights Institutions 2016).

### **5.7 Should a definition of the scope of a prohibition refer to treatments that are deferrable or irreversible, or should it use other concepts to define what treatments should be in scope? Why?**

As we state in our opening recommendations, we commend an approach that rules out some types of rationale for medical interventions (those conducted for social, cultural and their derivative psychosocial rationales), but that also articulates principles and norms.

Some medical interventions are justified as urgently necessary for physical health or survival. Hegarty and others identify clinical uncertainty regarding the necessity of some specified surgeries on children with intersex variations. They observe significant slippage:

*Health care professionals sometimes draw lines between interventions on grounds of anatomical variation alone. But they also often find it necessary to draw on a more phenomenological ontology in which bodies are situations*

*that human subjects experience. These participants were sometime aware that they did not operate on a “desert island” but in a context sometimes characterized by a dubious received wisdom about interventions, collective opposition to medicalization, parental anxiety, health care economics, the state’s role in child protection, and patients’ powers to make choices to demand or refuse particular interventions. [...]*

*The clearest example of the “prototype” of a medically necessary intervention here, being mentioned first and by many participants was the life-saving steroid interventions used to address salt-wasting CAH in infancy. Second, the continuum was not symmetrical but marked (Horn, 2001), as the nonessential pole had no equivalently common or readily accessible anchor, and its meaning was sometimes reconstructed; “. . . it may be a functional choice,” or relabeled (as “interventions that are helpful for the overall management of the family” for example). The definition of what medical necessity is seems far clearer and more coherent than the definition of what it is not. Third, while expert medical consensus favors clear and precise referential language in this domain (Lee et al., 2006), interviewees had clear preferences for vagueness in some areas. It was particularly difficult to specify what cognates of the word “function” mean, as they sometimes seemed to be discrete ways of talking about physical excretion or sexual practices, and sometimes seemed to refer to psychosocial experiences more loosely attached to those physical processes (Hegarty et al. 2020).*

A prohibition must have a conception of medical necessity that is tightly defined, for example, to permit interventions that are necessary to avoid serious, urgent and irreparable harm to the child or adolescent (Carpenter 2020b, 10). The existence of uncertainty in relation to some interventions means that we strongly recommend legislating for an oversight body or mechanism to bring together clinicians, human rights and child rights bodies and experts, and representatives of intersex-led organisations to ventilate these issues. Such a body can operate on a post-facto basis (i.e. after the fact), reviewing decisions where urgency or personal informed consent is asserted (Intersex Human Rights Australia 2018c). We describe such a body in our response to question 17.

An exemption in relation to ritual or routine male circumcision may be necessary, subject to separate and specific public debate. It should be noted that public hospitals in NSW no longer perform ritual or routine male circumcision due to the human rights implications of this intervention (Sydney Children’s Hospital at Westmead, Sydney Children’s Hospital, Randwick, and Kaleidoscope Children, Young People and Families 2015). Unusually, the Sydney Children’s Hospital Network does not apply to private hospitals, despite raising concerns about the human rights implications of ritual or routine male circumcision without the consent of the subject. Please see the discussion on the universality of human rights and the issue of ritual or routine male circumcision in the IHRA submission to the Australian Human Rights Commission inquiry (Intersex Human Rights Australia 2018b, 26–28).

In recommendation 7, the Tasmanian Law Reform Institute recommended an explicit exemption for transgender children ‘seeking to delay puberty or secondary sexual differentiation’. Unfortunately, the report authors lacked expertise on intersex issues and –

despite data on this issue being put to the Institute (Carpenter 2018b) – this recommendation fails to address the utility of such treatments for some non-transgender children with intersex variations. For example, in the Family Court case *Re: Carla*, puberty blockers were an alternative treatment that was discounted by the judge:

*this would require at least three monthly injections of depot Lucrin intramuscularly, three monthly medical reviews and any female pubertal development would thereby be necessarily delayed until her testes were removed and pubertal suppression could be ceased. This would mean that Carla's pubertal development would be significantly delayed compared to her peers with likely detrimental social and psychological effects on her in addition to detrimental physical effects including in respect of her bone health. Carla would, of course, also be exposed to the abovementioned significant risk of tumour development in the testes during this time (Family Court of Australia 2016)*

This decision presupposed the length of any delay in favour of surgery before the child commenced school and is markedly different to decisions by the Family Court involving transgender children, for example, the judge in the case *Re Lucy (Gender Dysphoria)* found that treatment with puberty blockers would be reversible and 'provide a hiatus until the child is "Gillick competent"' (Family Court of Australia 2013). Current statements by the WHO link gonadectomies in Carla's trait to female gender assignment; with the benefit of additional data on cancer risks, no statements about cancer risk are now made in relation to this child's diagnosis (Carpenter 2018a).

As stated in the Darlington Statement, existing distinctions between 'therapeutic' and 'non-therapeutic' have failed our population. In *Marion's case*, the majority judgment described a hesitation to use these terms 'because of their uncertainty. But it is necessary to make the distinction, however unclear the line may be' (High Court of Australia 1992), while Brennan J defined therapeutic as:

*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 (High Court of Australia 1992).*

The inclusion of 'cosmetic deformity' clearly facilitates a range of social, cultural and psychosocial rationales, as seen in discussion of feminising surgery and rationales for sterilisation in *Re Carla* (Family Court of Australia 2016), but the concept of a 'pathological condition' is also open to abuse, as identified in our response to question 1.

The key goal should be to ensure the effective operation of the legislation. In our view, this will require a combination of measures, including:

- A statement of guiding principles
- Statements about scope, including in relation to the kinds of treatments that are permitted and those that are not permitted
- The provision of oversight to ensure accountability and transparency.

In a context where the meaning of intersex, ‘disorder’ and ‘normal’ are contested, and where there is no clinical consensus on surgery timing, indications or evaluation of outcome (Lee et al. 2016), it is unsurprising that clinicians have asserted ‘a lack of universal interpretation of “medically necessary surgery”’ (Vora and Srinivasan 2020). It is notable that claims of consensus, claims of a lack of consensus on surgery, and a lack of shared interpretation of medical necessity, are each leveraged to justify continuation of present practices. This indicates that it is a particular set of values that underpins treatment.

However, there are shifts towards consensus in relation to medical necessity and genital cutting. A significant statement published in the American Journal of Bioethics by 91 academic and other authors known as the Brussels Collaboration on Bodily Integrity states that:

*a common understanding is that an intervention to alter a bodily state is medically necessary when (1) the bodily state poses a serious, time-sensitive threat to the person’s well-being, typically due to a functional impairment in an associated somatic process, and (2) the intervention, as performed without delay, is the least harmful feasible means of changing the bodily state to one that alleviates the threat (Earp 2019). “Medically necessary” is therefore different from “medically beneficial,” a weaker standard, which requires only that the expected health-related benefits outweigh the expected health-related harms. The latter ratio is often contested as it depends on the specific weights assigned to the potential outcomes of the intervention, given, among other things, (a) the subjective value to the individual of the body parts that may be affected, (b) the individual’s tolerance for different kinds or degrees of risk to which those body parts may be exposed, and (c) any preferences the individual may have for alternative (e.g., less invasive or risky) means of pursuing the intended health-related benefits (Darby 2015). (The Brussels Collaboration on Bodily Integrity 2019, 18)*

This definition of medical necessity owes much to Boorse in its reference to the notion of ‘functional impairment’, but the definition is strengthened by the prior reference to a ‘serious, time-sensitive threat’.

In our view, the references to ‘functional impairment’ and to ‘well-being’ are inadequate:

- not only do we share Ron Amundson’s concerns about the normativity evident in notions of functionality (Amundson 2000) but, as we describe below, discussion of multiple medical interventions on infants and children with intersex variations that are claimed as functional are actually social and cultural rationales,
- psychosocial rationales are purported to improve ‘well-being’, including claims about reduced risk of stigmatisation, albeit without evidence (Lee et al. 2016).

This seems unintended, as key authors rule out medical interventions for psychosocial and cultural rationales (see, for example, the paper cited by the Brussels Collaboration, Earp 2019; and also Earp et al. 2021; Earp 2021). However, our concerns are illustrated in the Senate Community Affairs References Committee report on involuntary or coerced

sterilisation in 2013, which referred to an interpolation of social and cultural rationales into a decision on surgery that might also be necessary to remove a threat of cancer:

*The committee is concerned that other matters such as 'sex of rearing' or 'likelihood of gender dysphoria' are interpolated into the discussion of cancer risk. This confusion between treatment options to manage cancer risk and treatment options to manage intersex could undermine confidence in the neutrality of those advocating for surgical interventions. (Senate of Australia Community Affairs References Committee 2013, 88)*

The Committee quoted a letter from a group of clinicians that was explicit about this, stating that 'sex of rearing', fertility, likelihood of gender dysphoria comprised part of decision-making on gonadectomies:

*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. (Senate of Australia Community Affairs References Committee 2013, 87)*

Cancer risks are not the only area where cultural matters are interpolated. A public submission to that Senate inquiry by the Australasian Paediatric Endocrine report identified '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, 3) as types of procedure conducted in Australia, stating 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. Surgery for psychosocial indications remains in contention both within Australasia and internationally, particularly for reduction of an enlarged clitoris, as tissue is being removed which the individual may wish was not removed later on (Australasian Paediatric Endocrine Group et al. 2013, 4)*

These surgeries are not only framed as 'for the purpose of appearance', they frame a cultural rationale (a perceived need to stand to urinate to be men)<sup>2</sup> as a functional rationale, and make assertions about management of psychosocial (i.e. well-being) risks – risks that the 2016 global update identifies as entirely unproven (Lee et al. 2016). The Australasian Paediatric Endocrine Group authors additionally report, in the following paragraph:

*There is limited evidence reporting long-term outcomes of early surgical management for reasons of appearance. The few outcome studies reported have conflicting results of good and poor outcomes (cosmetic, sexual, or*

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<sup>2</sup> This rationale provoked a particularly strong response on an occasion when Morgan Carpenter delivered training to staff and volunteers of People with Disability Australia, many of whom were men who use wheelchairs.

*psychological), with particular concern regarding sexual function and sensation (Australasian Paediatric Endocrine Group et al. 2013, 4)*

This suggests that surgeries to enable men to stand while urinating nevertheless give rise to ‘particular concern regarding sexual function’, and recognises variable outcomes related to well-being.

In our view, these examples illustrate how the Brussels Collaboration definition of medical necessity can be misused because of the references to functional impairment and well-being. However, the source paper for the Collaboration document by Brian Earp usefully describes medically necessary interventions as ‘least harmful’ methods of alleviating a threat, without reference to ‘functional impairment’, as those:

*where the bodily state in and of itself poses a serious and immediate threat to the person’s well-being, and the intervention is the least harmful way of changing the bodily state to one that substantially alleviates the threat (Earp 2019).*

We recommend employing a series of tests defined in the Yogyakarta Principles plus 10, combined with a test based on this work by Brian Earp. The Yogyakarta Principles plus 10 were constructed in discussion at a meeting of experts in Geneva in 2017 where draft new Principles were reviewed, analysed and redrafted. Participants included judges, parliamentarians, human rights and subject matter experts. We propose use of the Yogyakarta Principles plus 10 because of our concerns about the vagueness of the term ‘well-being’, and about inappropriate use of the term ‘functional’. Therefore, drawing on the Yogyakarta Principles plus 10, the proposed legislation should prohibit invasive or irreversible medical procedures that modify sex characteristics without an individual’s free, prior and informed consent, unless necessary to avoid serious, urgent and irreparable harm. This expression aims to address complexities in the meaning of ‘medical necessity’ and contains a four-part test:

- Does the procedure modify sex characteristics?
- Is the procedure invasive or irreversible?
- Has the individual given free, prior and informed consent?
- Is the procedure necessary to avoid serious, urgent or irreparable harm?

The tests provide abstract rules that distinguish inconsequential interventions from consequential interventions, and distinguish interventions that are necessary to prevent serious harm from those that do not have such a justification, for example, distinguishing interventions based on an established high risk of gonadal tumours from interventions based on gender stereotypes or social or cultural norms. Consequential interventions are those where erroneous assumptions and lack of necessity can cause ongoing harm to individuals subjected to medical interventions.

Drawing upon Earp (2019), the fourth part could be modified to read as follows:

- Is the intervention the least harmful way of avoiding or alleviating the serious, urgent or irreparable harm?

Nevertheless, the use of similar tests in Marion’s case (High Court of Australia 1992) justifies an explicit rejection of medical interventions without personal consent that are based on social, cultural and psychosocial factors. The following models provide good approaches to the identification of which procedures should be permitted:

- Californian Senate Bill 201 refers to deferability, necessity and specific interventions that are unambiguously necessary (Wiener 2019, 5), and also rules out specific interventions (Wiener 2019, 2–3).
- A bill presented to the Congress of Argentina defines ‘therapeutic procedures’ as those ‘strictly based on duly documented medical need related to serious present or future harm to a person's physical health or their life’ (Estévez 2020).

In our view, legislation must make provision for oversight in order to ensure transparency and accountability, and manage situations of uncertainty. Any legislative proposal will have limited antecedents and is likely to be subjected to gaming and testing. An oversight regime that has authority to consider a wider range of treatments and interventions than those explicitly prohibited is likely to be helpful. The legislating of guiding human rights principles and meaningful penalties for non-compliance can help to narrow or eliminate gaming. We discuss this issue further in response to question 17.

## **5.8 Should inclusion in scope depend on having a diagnosed variation in sex characteristics?**

No. The goal should be to eliminate harmful practices irrespective of diagnosis or terminology, and it should not entrench a medicalised approach to determining access to protection.

Clinical diagnoses change over time in both large and small ways, and umbrella terms are gamed and contested in ways that promote exclusion of specific populations (H. Meyer-Bahlburg 2005; González and Ludwikowski 2016; Griffiths 2018). The naming of specific diagnoses in legislation may even promote such change. Inclusion of specific diagnostic language in legislation may also delay or hinder diagnosis in favour of pre-emptive treatment.

Generally, diagnoses are at present changing due to a shift in diagnostic capabilities occasioned by developments in genomics. Diagnostic terms are shifting from descriptive terms based on clinical signs or histology (such as ‘androgen insensitivity’ or ‘androgen resistance’) to terms based on chromosomal traits. Most individuals lack genetic diagnoses, for example, a 2016 Australian study reported an increase in the percentage of individuals with intersex variations receiving a genetic diagnosis from 13% to 35% (Eggers et al. 2016). Non-genetic forms of diagnosis are imprecise and individuals may find that their diagnoses change over time, sometimes in very significant ways, related to their medical treatment (for an example, and discussion of personal consequences, see Kelleher 2020). Limitations in diagnostic methods are an indication of why a diagnosis is inappropriate as a prerequisite for protection.

A large number of intersex organisations have objected to the adoption of ‘disorders of sex development’ terminology in the International Classification of Diseases 11 (Intersex Human Rights Australia 2019).

IHRA (represented by Morgan Carpenter) and GATE (represented by Mauro Cabral Grinspan) are currently contracted to the World Health Organization in relation to intersex health and human rights. Discussions on a related submission to the WHO (Carpenter and Cabral 2017) are ongoing. Changes to diagnostic terms are possible in coming years.

### **5.9 How should a definition be crafted to allow health professionals to undertake treatments that affect sex characteristics, but which are being undertaken for reasons unrelated to intersex status?**

Human rights are universal and should apply to all children – but some forms of genital mutilation likely require separate public debate, or are already prohibited in some circumstances. The existence of both scenarios is helpful, meaning that multiple types of non-inclusion exist. A bill might seek to:

- refer to legislative provisions on FGM in relation to that practice, and ensure that new provisions are consistent
- exempt ritual or routine male circumcision, subject to separate public debate.

In relation to ritual or routine male circumcision, please see the discussion on the universality of human rights and the issue of ritual or routine male circumcision in the IHRA submission to the Australian Human Rights Commission inquiry (Intersex Human Rights Australia 2018b, 26–28).

In relation to female genital cutting, the UN OHCHR background note also identifies how legislation on FGM can contain exemptions permitting surgeries on children with intersex variations, as is the case in the ACT:

*In some countries, legislation prohibiting female genital mutilation may contain explicit exemptions permitting so called “normalizing” surgeries on intersex children, despite provisions stating that social, cultural and religious customs or practices cannot justify their necessity (Office of the High Commissioner for Human Rights 2019)*

Model law on FGM does not contain any reference to consent, and an exemption permitting a ‘sexual reassignment procedure’ on ‘a person whose sex is ambivalent’ similarly lacks reference to consent (Australian Capital Territory 2018, sec. 77 (2)).

It should be noted that many forms of female genital cutting persist in medicine in Australia and have been the subject of clinical discussion. For example, in 2015, the Royal Australian College of General Practitioners published a resource on ‘female genital cosmetic surgery’ that followed a Medicare review of vulvoplasties that found a significant increase in

numbers of such procedures (Carpenter 2018b). In such a context, distinctions between FGM and ‘female genital cosmetic surgery’ risk being determined by racial stereotypes, where surgery is permissible on non-racialised subjects, but not those with family heritage from regions where FGM is still practiced (The Brussels Collaboration on Bodily Integrity 2019; Earp and Johnsdotter 2020; Shahvisi and Earp 2018).

We note that the structure of this question has changed between draft and final discussion papers, and that the draft question referred specifically to male circumcision. The format of the new question is likely to provoke debate that seeks to exclude so-called ‘disorders of sex development’ such as hypospadias and congenital adrenal hyperplasia from a definition of intersex (González and Ludwikowski 2016; Griffiths 2018; H. Meyer-Bahlburg 2005). As noted by Morgan Carpenter, processes of clinical definition have each been followed by processes of narrowing, exclusion and redefinition through claims of vagueness, inappropriateness and references to stigma; for example, the term ‘hermaphrodite’ was replaced by ‘pseudo-hermaphrodite’ and ‘true hermaphrodite’, the term intersex itself was replaced in clinical settings by ‘disorders of sex development’, and current trends are to seek exclusion of diagnoses originally encapsulated in these terms and narrow the term intersex to situations where some uncertainty is expressed about gender (Carpenter 2018b; H. F. L. Meyer-Bahlburg 2017; González and Ludwikowski 2016). These processes are flawed for multiple reasons. Firstly, future gender identity cannot be predicted with certainty irrespective of diagnosis, even for individuals with typically female or male bodies. Secondly, current shifts presuppose the correctness of human rights violations to ‘normalise’ sex characteristics in certain cases, and there is a risk that the purpose of such exclusion is to perpetuate existing medical practices to the greatest extent possible (Carpenter 2020b). Thirdly, replacing the language has not avoided stigma; it is more the case that shifts in clinical language reflect clinical authority over a marginalised population, and that clinical practices exemplify stigma. Certainly, the clinical global update of 2016 identifies that there is no evidence that medical interventions address stigma (Lee et al. 2016), and the Senate committee report of 2013 identifies as a circular argument the idea that psychosocial rationales for surgery address stigma and parental bonding (Senate of Australia Community Affairs References Committee 2013, para. 3.128).

For the avoidance of doubt, procedures such as hypospadias repairs, surgery to the genitals of children with congenital adrenal hyperplasia and hormonal interventions (for example, on children with sex chromosome variations or to commence puberty) must be included in a prohibition of surgery without personal consent (Carmack, Notini, and Earp 2015; Hegarty et al. 2020; Fichtner et al. 1995; González and Ludwikowski 2014, 2016).

### **5.10 How should exceptions be described to allow clarity while avoiding overly wide interpretation of exceptions?**

ACT legislation already prohibits FGM and duplication is not required. The California Senate bill 201 provides an example of a strong listing of surgical inclusions and exemptions. We recommend implementation of broad statements of principles and implementation of oversight combined with narrow specification of exemptions.

### **5.11 Should the regulation of medical interventions be based on a definition of “intersex” as a category of person, or should it be designed based on circumstances or principles?**

The regulation and prohibition of certain medical interventions should not be based on a definition of intersex as a category of person. It should be based on circumstances and principles, as described in responses above.

In this regard, we note that the definition of intersex in the *Discrimination Act* has been replaced, but the existing definition of intersex in the *Legislation Act 2001* defines intersex people in relation to deficits and without reference to their innate character. The definition’s focus on deficits is stigmatising. The definition has also been misrepresented as necessarily defining the legal status of intersex people as not female or male, or as representing intersex people as having a particular identity. Because of its lack of acknowledgement of temporality or the innate character of intersex traits, it is misleading and includes people who, for example, undergo medical gender affirmation (see, for example, Carpenter 2017; Intersex Human Rights Australia 2012).

As of the *Births, Deaths and Marriages Registration Amendment Act 2014* (ACT), the term intersex is used in the ACT to refer to a sex category for the purposes of recording births. This is in conflict with the goals of this legislation, such that an attempt to prohibit surgeries on intersex children in the ACT might have no effect, as no children have been recorded as belonging to that classification.

In our correspondence and meetings with Attorney-General Simon Corbell MLA in relation to the 2014 legislation, and with other parties, we opposed this use of the term intersex, asserting that it was an inappropriate reuse of a definition from anti-discrimination law.<sup>3</sup> The provisions in the original (federal) anti-discrimination law were intended to enable access to a provision of law by individuals *perceived* to be intersex and eliminate a then-proposed ‘bona fide’ requirement to receive protections in law (Carpenter and Organisation Intersex International Australia 2012). They have been misused in a case brought before the High Court (DLA Piper Australia 2014), and they mislead the public and policy-makers. Definitions of ‘sex characteristics’ in the Yogyakarta Principles and elsewhere have been constructed in part in response to these misuses. The inappropriate utilisation of the term intersex by Access Canberra should be discontinued at the earliest opportunity.

A replacement definition, ideally based on a definition used in the UN OHCHR Background Note (Office of the High Commissioner for Human Rights 2019), could assist in resolving this situation by decoupling intersex from any sex classification. However, ACT legislation and regulation should not need to define intersex, any more than it needs to define other stigmatised populations.

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<sup>3</sup> As with contemporaneous correspondence from Katy Gallagher, then Chief and Health Minister, we have retained copies of this correspondence, which we can supply on request.

### **5.12 If regulation of medical intervention should be based on intersex status, how should intersex be defined?**

Regulation and prohibition should not be based on intersex status. Please see our detailed response to the preceding question (question 11). ‘Sex characteristics’ should be used, in line with the Darlington Statement (AIS Support Group Australia et al. 2017) and Yogyakarta Principles (Yogyakarta Principles 2017), and also in line with Maltese legislation (Malta 2018).

### **5.13 If a prohibition is based on circumstances (e.g. “alteration of sex characteristics”) or principles (e.g. “with the consent of the individual”), rather than limited to a category of people, how would such a definition affect cases not related to intersex status, such as male circumcision?**

Ritual or routine male circumcision should be explicitly excluded as out of scope, pending specific public debate. Other proposed exemptions should be named and carefully considered, and potentially subjected to formal oversight.

Legislation should include an explicit exemption relating to ritual or routine male circumcision. This may then be the subject of discussion by the government and/or Assembly, providing an opportunity for amendment.

### **5.14 How can we best support the consent of a parent to make choices that preserve the consent of the child in a medical setting?**

The consent of an adolescent should be required in all cases where medical intervention does not address a serious, urgent and irreparable harm. We do not propose that Gillick competency be replaced; our preference is for deferral of interventions that can be deferred until individuals can consent. Clinically speaking, early forms of consent may be regarded as ‘assent’, and subject to risks of parental and clinical coercion. This is challenging to identify and address. The ability to defer treatment, the institutionalisation of independent peer support and advocacy, and the implementation of oversight mechanisms seek to address such risks. Supported decision making by adolescents and adults should be facilitated as much as possible.

In emergency situations, requirements for prior consent are understood to be impractical. In cases where medical intervention is asserted to address a serious, urgent and irreparable harm in a child is too young to assent – for example, when a neonate is unable to urinate – the consent of parents or guardians should be secured wherever practicable, as is already the case. Parties to these decisions should be aware that necessary surgery does not provide the opportunity for additional simultaneous surgeries with different rationales (there is a discussion on this issue in chapter 5 of Senate of Australia Community Affairs References Committee 2013).

The UN CRC frames parental authority as relating to procedures that are necessary, that is, procedures that do not conflict with the right to bodily integrity and autonomy. It does this by acknowledging a principle that parental authority to make decisions is to be respected, while also calling for prohibitions of “coerced sterilization or unnecessary medical or surgical treatment”. Parental rights are not unfettered. The same principles apply in relation to female genital mutilation.

Supporting decision making by parents requires attention to the availability and utilisation of peer support and associated services, as we describe in our response to question 3. There is a risk that removal of surgery as a standard practice will be perceived as removing the only available treatment path from parents and their children. As identified by Liao and others (Liao, Wood, and Creighton 2015; Hegarty et al. 2020), it is essential that action to eliminate harmful practices be accompanied by effective psychosocial support without perpetuating a harmful medical model. These actions might include:

- Provision of a psychologist and social worker for families and individuals, by Intersex Peer Support Australia.
- Provision of resourcing for an intersex-led peer support organisation (such as Intersex Peer Support Australia) to provide support to parents, families and children irrespective of their experience of their (or their child’s) gender identity or experience of gender.
- Provision of support for systemic and individual advocacy, including a social worker, a bioethicist or lawyer, and a communications staffer, modelled on the disability movement, by Intersex Human Rights Australia.

### **5.15 What if any procedural requirements should be met in order to consider that consent is freely given and fully informed?**

Framing consent as a procedure risks reducing it to a one-off tick-box to be completed as part of a preordained process. Consent processes are ongoing and should be subject to formal oversight.

Please also see the relevant discussions in the IHRA submission to the Australian Human Rights Commission inquiry (Intersex Human Rights Australia 2018b, 39–56).

Clinicians are frequently blunt in describing the ways that they educate parents and children to understand bodies in particular pathological ways, including through the strategic use of clinical uncertainty (Timmermans et al. 2018), and in situations where parents may be otherwise unaware of any difference in their child (O’Connor 2016). Streuli and others describe an experiment where medicalised and non-medicalised information produce endorsement of different treatment outcomes (Streuli et al. 2013).

In the experience of some members of IHRA, consent by a child or adolescent can be unduly informed by a lack of awareness of alternatives, by coercion or long-term experiences of education, and by conceptions of ‘normality’ that presuppose a need for surgical or hormonal intervention. These experiences are also described in Australian sociological

research that shows experiences of pressure from clinicians and parents to conform to gendered social expectations (T. Jones et al. 2016). In our view, these issues can only be adequately addressed through education and awareness raising (see, for example, Brömdal et al. 2020), and through access to peers. These issues highlight the importance of peer support, inclusive education, and awareness raising about intersex lives.

### **5.16 What decision-making approaches could be effective in ensuring decision-makers, including parents, have sufficient support to make decisions that uphold children's rights and best medical practice?**

There is a risk that removal of surgery as a standard practice will be perceived as removing the only available treatment path from parents and their children. As identified by Liao and others (Liao, Wood, and Creighton 2015; Hegarty et al. 2020), it is essential that action to eliminate harmful practices be accompanied by effective psychosocial support without perpetuating a harmful medical model. These actions might include:

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- Provision of support for systemic and individual advocacy, including a social worker, a bioethicist or lawyer, and a communications, education and training staffer, modelled on the disability movement, by Intersex Human Rights Australia.

Guidelines are inadequate as a decision-making tool due to a lack of prerequisites, including clinical consensus and agreement of other stakeholders (please see Carpenter 2020a). Concerns with clinical practices in areas of uncertainty or disagreement are evident in multiple areas, not only in relation to intersex health and human rights. In a current article in the American Journal of Bioethics, Alex London describes the situation of an 'absence of explicit guidance for responding to cases in which there is significant uncertainty or disagreement about the relative therapeutic, prophylactic or diagnostic merits of available interventions' as an incomplete statement 'of the core ethical and professional responsibilities of medical professionals ... in ways that threaten fundamental goals of medicine' through 'a lingering vestige paternalistic overreach' (London 2021). London calls for the inclusion of a new duty in statements of medical ethics, to support 'scientifically sound and socially valuable studies' – without compromising patient rights and interests.

ACT and other Australian governments should make provisions to resource incremental development of life-time standards of care based primarily on community inputs of the types provided for in answer to this question.

Oversight is essential to ensure that patient-centred decision-making is not parent-centred decision-making (Timmermans et al. 2018).

Peer support workers and/or a psychologist or social worker from Intersex Peer Support Australia and a bioethicist or other qualified nominee from Intersex Human Rights Australia should be present in clinical multidisciplinary teams, and resourced appropriately to be so. Communications, training and education skills are needed to promote effective school and clinical curricula, and also promote public awareness.

**5.17 Should there be an independent or advisory body or person involved in intersex medical intervention decision-making? If an independent body or person plays a role to support decisions around medical interventions on intersex people:**

**a) What should that be?**

**b) How should it operate?**

**c) What categories of decisions should be within its remit?**

Yes. In our view, legislation must make provision for oversight in order to ensure transparency and accountability, and manage situations of uncertainty (for example, uncertainty or contention about interpretations of medical necessity). Any legislative proposal will have limited antecedents and is likely to be subjected to gaming and testing. An oversight regime that has authority to consider a wider range of treatments and interventions than those explicitly prohibited is likely to be helpful. The inclusion in legislation of guiding human rights principles and meaningful penalties for non-compliance can help to narrow or eliminate gaming. The oversight body should contribute to, and periodically review, standards of care.

Please see the discussion on oversight in the IHRA submission to the Australian Human Rights Commission inquiry, and also the discussion in the IHRA and People with Disability Australia submissions to the Australian Law Reform Commission review of the family law system (Intersex Human Rights Australia 2018b, 2018a, 2018c; People with Disability Australia 2018b, 2018c).

An oversight body could be a committee hosted by the ACT Human Rights Commission. If that is impractical for some reason, then the Public Trustee and Guardian might be a suitable location (though we note that the concepts of guardianship are incompatible with the CRPD).

The oversight body should be comprised of 1/3 community members with relevant human rights, legal, bioethical or psychological expertise, 1/3 human rights and child rights experts, and 1/3 clinicians (including allied health) involved with provision of care to individuals and families.

It should be able to discuss anonymised case information and relevant literature, and make decisions on the appropriateness of treatment. It should be empowered to receive post-hoc (after the event) reports on medical interventions where urgent necessity or personal informed consent are asserted. It should be empowered to receive adequate short- and long-term follow-up reports on cases brought to it. Proceedings should be confidential, but

periodic summary reports should be published. The oversight body should be tasked with investigation of cases of harmful practices.

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