



9 August 2021

Submission on the ACT government options paper on ‘Protecting the rights of intersex people in medical settings’

Submitted by Intersex Human Rights Australia (IHRA)

Endorsed by Intersex Peer Support Australia (IPSA) and Mani Mitchell (executive director of Intersex Trust Aotearoa New Zealand)



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2 About this submission

Thank you for publishing the regulatory options paper on ‘Protecting the rights of intersex people in medical settings’ (Chief Minister, Treasury and Economic Development Directorate 2020) and inviting feedback.

We warmly welcome the leadership and work of the ACT government on this issue, and the commitment by Chief Minister Andrew Barr and his Department to implement human rights protections.

This is a formal response by Intersex Human Rights Australia (IHRA). It has been written by Morgan Carpenter, M.Bioeth (Sydney), M.InfTech (UTS), executive director of IHRA. It has been supported through review and feedback by our board of directors, and it also builds on discussions with community members, legal practitioners, Equality Australia and other stakeholders regarding proposed reforms in Victoria and a potential model bill.

This submission is endorsed by Intersex Peer Support Australia (IPSA) and Mani Mitchell, Dip. T., Dip. Ed., Dip. Counsel., MNZAC, ITTA Counsellor, executive director of Intersex Trust Aotearoa New Zealand.

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. Mani Mitchell, executive director of ITANZ, has endorsed this submission.

4 General principles and recommendations

Our submission is grounded in the following principles, papers and processes:

- 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, and general recommendations by the Committee on the Rights of the Child, the Committee on the Elimination of Discrimination against Women, and the Committee on the Rights of Persons with Disabilities.
- The Australian Law Reform Commission report on Equality, Capacity and Disability in Commonwealth Laws (Australian Law Reform Commission 2014).
- Our submissions on inquiries by 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 2018a, 2018b).
- Our submission to the ACT government in response to the “Key issues in the prohibition of deferrable medical interventions on intersex children: Discussion paper” submitted in January 2021 (Carpenter and Intersex Human Rights Australia 2021).
- Discussions with community members, subject matter experts, legal institutions, and Equality Australia.

UN Treaty Body recommendations to Australia by the Committee on the Rights of the Child, the Committee on the Elimination of Discrimination against Women and the Committee on the Rights of Persons with Disabilities leave no doubt that involuntary and unnecessary medical treatments on people with innate variations of sex characteristics fail to protect the integrity of the person, and are “harmful practices” that must be prohibited. For example:

The Committee urges that the State party to [...] Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary surgical or other medical procedures on intersex children before they reach the legal age of consent, implement the recommendations made by the Senate in 2013 on the basis of its inquiry into the involuntary or coerced sterilization of intersex persons, provide adequate counselling and support for the families of intersex children and provide redress to intersex persons having undergone such medical procedures (Committee on the Elimination of Discrimination against Women 2018, 26).

5 Responses to questions in the discussion paper

5.1 Question 1a: Age or capacity?

Whether or not the proposed legislation responds to issues affecting only minors, or additionally includes adults, it will need to address the circumstances identified in the following three scenarios:

- people who have legal capacity (for example youth and adults who are able to demonstrate ‘Gillick competency’).
- people where legal capacity is questioned (including children, youth and adults), and
- people who do not have legal capacity (for example, infants and young children, as well as some older people who may have intellectual disabilities).

We would prefer to see legislative proposals that respond effectively to each of these scenarios in both adults and minors. In the alternative, if the ACT government determines to focus only on minors, we believe that each scenario should be addressed in minors.

In our view, legislative proposals should reflect the view that all individuals – including adults and minors with variations of sex characteristics, and parents, carers or family members – need support to make treatment decisions freely and effectively.

In line with the recommendations of the Committee on the Rights of Persons with Disabilities (Committee on the Rights of Persons with Disabilities 2019, 2014) and the National Decision-Making Principles set out by the Australian Law Reform Commission (2014), individuals with variations of sex characteristics should be supported to make decisions to the maximum extent possible. The National Decision-Making Principles:

Principle 1: The equal right to make decisions

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Support

Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will, preferences and rights

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

Principle 4: Safeguards

Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence (Australian Law Reform Commission 2014, 64)

These Principles should be applied to the circumstances of children and adolescents in line with the evolving capacity of the child, and informed by up-to-date interdisciplinary research on a child's capacities to express a personal view on issues affecting them (Alderson 2017; Smith and Coady 2019).

5.1.1 Principle 1: The equal right to make decisions

In line with these Principles, substitute decision-making authority, whether in the hands of clinicians, parents, carers or an oversight body, should always be a last resort. In every case, implementation of these Principles must ensure that the "will, preferences and rights of persons direct decisions that affect their lives" (Australian Law Reform Commission 2014, 64).

A need for supported decision-making should not be used to question a person's legal capacity (Committee on the Rights of Persons with Disabilities 2014, para. 33), and should not be limited by claims of disproportionate or undue burden (Committee on the Rights of Persons with Disabilities 2014, para. 34).

5.1.2 Principle 2: Support

The Committee on the Rights of Persons with Disabilities has remarked on the need for non-medical information and independent support:

States parties must [...] respect the legal capacity of persons with disabilities to make decisions at all times, including in crisis situations; must ensure that accurate and accessible information is provided about service options and that non-medical approaches are made available; and must provide access to independent support (Committee on the Rights of Persons with Disabilities 2014, para. 42).

The Australian Law Reform Commission has expressed concern at a lack of available supporters, identifying a need for resourcing (Australian Law Reform Commission 2014, 69). Legislation should provide for the implementation of supported decision making, including the resourcing of an appropriate infrastructure. Legislation should also ensure the provision of biomedical information, and also non-clinical information including Australian human rights and patient rights information

It is our preference that individuals, families and carers – including family members and carers acting as supporters – should be supported by independent service providers, such as Australian charities led by people with innate variations of sex characteristics. We recommend maximising the role of Australian charities led by people with innate variations of sex characteristics; these organisations include experts in psychology, bioethics, social work, child and adolescent development, and health law, and are well-placed to take on these roles, subject to receiving the requisite resources.

An oversight body should be tasked with oversight of service providers and standards necessary to safeguard the rights of persons being supported to make decisions.

5.1.3 Principle 3: Will, preferences and rights

The Australian Law Reform Commission carefully formulated the Principle that:

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives” (Australian Law Reform Commission 2014, 75).

This draws attention not only to will and preferences but also rights. The will, preferences and rights of children must be ascertained to the maximum extent possible.

The framework proposes two alternative scenarios, either a person being supported to choose a supporter, or the appointment of a representative. We support their adaptation to meet the needs of children, and we support recommendation 3-3 of the Australian Law Reform Commission report in relation to guidelines for supported decision-making and representative decision-making:

Recommendation 3–3 Will, Preferences and Rights Guidelines

(1) Supported decision-making

- (a) In assisting a person who requires decision-making support to make decisions, a person chosen by them as supporter must:
 - (i) support the person to express their will and preferences; and*
 - (ii) assist the person to develop their own decision-making ability.**
- (b) In communicating will and preferences, a person is entitled to:
 - (i) communicate by any means that enable them to be understood;*
 - and*
 - (ii) have their cultural and linguistic circumstances recognised and respected.**

(2) Representative decision-making

Where a representative is appointed to make decisions for a person who requires decision-making support:

- (a) The person’s will and preferences must be given effect.*
- (b) Where the person’s current will and preferences cannot be determined, the representative must give effect to what the person would likely want, based on all the information available, including by consulting with family members, carers and other significant people in their life.*

- (c) *If it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person's human rights and act in the way least restrictive of those rights.*
- (d) *A representative may override the person's will and preferences only where necessary to prevent harm (Australian Law Reform Commission 2014, 77)*

In our view, early, age-appropriate disclosure about bodies and their potentials, and community connection are vital.

5.1.4 Principle 4: Safeguards

Supported decision-making must safeguard against undue influence. The Committee on the Rights of Persons with Disabilities states that:

Undue influence is characterized as occurring, where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation. Safeguards for the exercise of legal capacity must include protection against undue influence; however, the protection must respect the rights, will and preferences of the person, including the right to take risks and make mistakes. (Committee on the Rights of Persons with Disabilities 2014, para. 22)

Currently, the following circumstances apply:

- Gender stereotypes and “generalised assumptions about some imaginary standard child” (Alderson 2017) can underpin medical rationales that superficially appear objective and that are inattentive to the rights of the child.
- Individuals and families may have been provided with information on inappropriate foreign support organisations,¹ or those led by clinicians and parents who exclude human rights-affirming narratives from consideration (Carpenter 2021). Individuals and parents and carers may not be aware of non-clinical forms of understanding variations of sex characteristics.
- Reports on clinical practices have identified significant concerns with the provision of information that presumes a need for surgical intervention and that is difficult for parents and individuals to challenge due to the epistemic authority of clinicians (Timmermans et al. 2018; Hegarty et al. 2020; Vavilov et al. 2020; Davis 2011; Lohman and Lohman 2018).
- Individuals may grow up experiencing hermeneutical injustices where they are unable to understand their bodies except through a biomedical perspective that disorders their bodies (Carpenter 2018b; Bastien-Charlebois 2015).

¹ For example, clinical resources available to people in Victoria and nationally (Carpenter 2021), and a 2020 journal article by Australian paediatric endocrinologists (Vora and Srinivasan 2020) refer parents to DSD Families, a UK organisation linked to the anti-trans, anti-gender movement in that country.

To address concerns about undue influence, particularly in an area of medicine that has sought to exclude and devalue non-clinical forms of knowledge including human rights affirming perspectives, it is our position that supporting information and resources must include biomedical information, and non-clinical information including Australian human rights and patient rights information.

Legislation should establish norms about the 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 the provision of non-medicalised information and peer support (Streuli et al. 2013; Timmermans et al. 2018; Roen and Hegarty 2018).

5.2 Question 1b: Population scope

IHRA prefers legislation that is universalist in scope, that eliminates harmful practices that modify sex characteristics irrespective of the population. This approach has the advantage of recognising that all people have the same human rights, including the rights to bodily integrity, autonomy and self-determination. This approach also reduces the risk of definitional gaming, where individuals seek to avoid a prohibition or scrutiny by claiming – or even by securing regulatory changes – that an individual is outside the scope of the legislation. Definitional gaming can also occur when groups or individuals lobby to remove particular innate variations of sex characteristics such as hypospadias and congenital adrenal hyperplasia from within the scope of potential legislation. A further problem may arise if particular manifestations of recognised variations are argued to fall outside the definitional category.

In our view, legislation must also aspire to universality and be grounded in normative human rights principles in order to have legitimacy. To this end, we have proposed that the ACT government legislate recognition of the right to bodily integrity, a desire to eliminate harmful practices in medical settings, and a right to access treatment with consent (Carpenter and Intersex Human Rights Australia 2021).

However, we recognise the importance of pragmatic approaches that address the circumstances only of people with innate variations of sex characteristics, and we acknowledge that this is the approach favoured by the ACT government in the options paper. We have heard arguments that a narrow approach avoids issues relating to overlapping populations, for example, avoiding an impact on gender diverse youth seeking medical intervention. However, we note that some youth with innate variations of sex characteristics are gender diverse, and their needs and human rights should be reflected in legislation just as much as cisgender youth with innate variations of sex characteristics. Similarly, some people with innate variations of sex characteristics have intellectual impairments or other disabilities, and intersections with the broader population of people with disabilities cannot be avoided.

The ACT government has reported that legislation to protect the human rights of people with innate variations of sex characteristics in medical settings “would not be legally radical and would be consistent with orthodox legal thinking about child welfare” (Chief Minister, Treasury and Economic Development Directorate 2021a), but this warmly welcomed legislative proposal addresses longstanding but neglected demands for reform.

Taking a pragmatic approach should allow for legislation to be reviewed and potentially extended to address the circumstances of gender diverse youth and people with disabilities. Our discussions have found an appetite for such reform by disability advocates, while recent Family Court decisions in cases involving gender diverse adolescents have given cause for concern for that population (see, for example, Jowett and Kelly 2021). Such extension would not only allow for the principles of legal protections to be fully realised, it would also be a marker of success for this project.

The rest of this paper presumes that a narrow scheme, only for people with innate variations of sex characteristics, will be considered for implementation.

The risks of definitional gaming rise when the scope of the legislation is narrowed. Equality Australia have proposed an approach that combines a general statement with a non-exhaustive list of current diagnostic terms (Equality Australia 2021, 12–13), and we commend this approach – however, we have reviewed and modified their language relating to population scope to arrive at the following proposal:

(a) a natural person with innate variations of sex characteristics that differ from medical or biological norms for male or female bodies;

(b) without limitation to (a), a natural person with innate variations (whether diagnosed or not) known as:

- *5-Alpha reductase deficiency*
- *17-Beta-Hydroxysteroid Dehydrogenase Deficiency or 17β-Hydroxysteroid Dehydrogenase III Deficiency*
- *47XXY or Klinefelter Syndrome, and variations such as 48XXXY, 49XXXXY*
- *Androgen Insensitivity Syndromes, or Androgen Resistance, including Complete, Partial and Mild forms*
- *Aphallia*
- *Bladder Exstrophy or Ectopia Vesicae*
- *Clitoromegaly, also known as large clitoris*
- *Congenital Adrenal Hyperplasia, including Classic and Late-Onset forms*
- *Cryptorchidism, also known as Undescended Testes*
- *de la Chapelle syndrome, also known as XX Male syndrome*
- *Disorders or Differences of Sex Development*
- *Epispadias*
- *Follicle-Stimulating Hormone Insensitivity*
- *Fraser Syndrome*
- *Gonadal Dysgenesis, including Partial and Complete forms*

- *Hypospadias*
- *Kallmann Syndrome*
- *Leydig Cell Hypoplasia*
- *Micropenis*
- *Mosaicism involving Sex Chromosomes, including XY/X0 and other variations*
- *MRKH, Mullerian Agenesis; Vaginal Agenesis; congenital absence of vagina*
- *Mullerian (Duct) Aplasia*
- *Ovo-testes, formerly ‘true hermaphroditism’*
- *Persistent Mullerian Duct Syndrome*
- *Polycystic Ovary Syndrome/Hyperandrogenism*
- *Progestin Induced Virilisation*
- *Swyer Syndrome, also known as XY gonadal dysgenesis*
- *Turner Syndrome, also known as X0, where a sole X chromosome is present*
- *Triple-X Syndrome (XXX)*
- *XY-Turner Syndrome*
- *XYY Syndrome, also known as Jacobs Syndrome*

Our proposed definition in part (a), above, seeks to avoid reliance on a definition that requires clinicians to determine a body as differing from norms. While the idea that a body meeting clinical norms should undergo medical intervention to modify sex characteristics is unlikely, the lack of protections for bodies deemed by clinicians to be within norms is plausibly a risk.

The listing in part (b) is adapted from a European “DSD-life” survey and papers by interACT and Equality Australia (Kreukels et al. 2018; interACT: Advocates for Intersex Youth 2020; Equality Australia 2021). We recommend that legislation ensure that the listing in (b) is explicitly stated to be non-exhaustive.

Additionally, medicine in this area is presently shifting from diagnoses based on clinical signs or clusters of symptoms to diagnoses based on genetics. Diagnoses such as androgen insensitivity encapsulate a heterogeneous population with diagnoses graded according to clinical signs, but androgen insensitivity has very many distinct genetic origins. This shift is facilitating genetic diagnosis (and elimination from the gene pool), but it is also changing individuals’ diagnoses. The introduction of language to refer to traits “known or formerly known” may be appropriate.

5.3 Question 1c: Exemptions

Medical emergencies and medical urgency are appropriate exemptions. These exemptions need to be drawn carefully, as illustrated below.

5.3.1 Gender stereotypes and “appropriate functioning”

While an inability to urinate is a clinical emergency, claims of “appropriate functioning” can be associated with social and cultural norms and gender stereotypes.

As an illustration of this conflation of function and a gender stereotype, Helen McArdle, the Tasmanian president of the Australian Medical Association, claimed that boys need to be able to stand to urinate in an ABC News report in April 2021:

“If surgery is required to enable appropriate functioning, as opposed to gender reassignment, then it may be that we shouldn’t wait until a child is 18 to undertake the consent, because that could cause a lot of health problems in the meantime,” Ms McArdle said.

“If say a boy can’t go to the toilet appropriately, then it may be that the surgery is necessary for medical reasons.” (McLennan 2021)

These statements used language that both journalists and readers will find difficult to parse. To explain, the reference to a boy going “to the toilet appropriately” is an oblique reference to a scenario where a boy is not able to urinate standing up. This is constructed as a medical problem of function that requires surgical intervention. The idea that men must not be forced to urinate sitting on a toilet is constructed as a strictly biomedical issue of function, obscuring the gender-based cultural or social stereotype that it relies upon.²

5.3.2 Gender stereotypes and cancer risks

The Senate Community Affairs References Committee expressed concern in a 2013 report regarding the interpolation of gender stereotypes and other non-clinical factors into clinical decision-making that proposes surgery to manage a high risk of cancer, and potential for “perceived or communicated risk” to become elevated, stating:

- *The complexity and diversity of cancer risk can become oversimplified, potentially elevating the perceived or communicated risk. Alternative monitoring options may be overlooked.*
- *The committee is concerned that other matters such as 'sex of rearing' or 'likelihood of gender dysphoria' are interpolated into the discussion of cancer risk. This confusion between treatment options to manage cancer risk and treatment options to manage intersex could undermine confidence in the neutrality of those advocating for surgical interventions. (Senate of Australia Community Affairs References Committee 2013, para. 4.28)*

A 2016 Family Court case not only illustrates these concerns, but was only possible through a failure of Australian governments to act on the recommendations of the 2013 report.³ The judge in the case, *Re: Carla (Medical procedure)*, appealed to medium cancer risks in a

² In addition to these comments, we note that deferral until age 18 has never been a position in the Darlington Statement nor in submissions by IHRA or other charities led by people with innate variations of sex characteristics.

³ We cited correspondence from then Chief and Health Minister of the ACT, Katy Gallagher, in January 2014 in our response to the December 2021 Discussion Paper on key issues in a legal prohibition (Carpenter and Intersex Human Rights Australia 2021).

determination that parents could authorise the sterilisation of a pre-school child with 17-beta hydroxysteroid dehydrogenase 3 deficiency (Family Court of Australia 2016, para. 19). The evidence in an obsolete 2006 clinical “consensus statement” was mis-cited: the statement identified “medium risk” but recommended the monitoring of gonads in children with this trait, not their removal (Hughes et al. 2006, 558). Later clinical reports lowered that risk (Pleskacova et al. 2010) and a 2018 journal article by Morgan Carpenter was able to identify clinical recommendations that associate sterilisation in this child’s trait only with female assignment (Carpenter 2018a), citing the World Health Organization International Classification of Diseases 11 Foundation code information for 17-beta hydroxysteroid dehydrogenase 3 deficiency, which states:

If the diagnosis is made at birth, gender assignment must be discussed, depending on the expected results of masculinizing genitoplasty. If female assignment is selected, feminizing genitoplasty and gonadectomy must be performed. Prenatal diagnosis is available for the kindred of affected patients if the causal mutations have been characterized (World Health Organization 2020).

This shows that gonadectomy is not recommended in cases where assignment is male. Not coincidentally, the judge in *Re: Carla (Medical procedure)* relied extensively on unusually detailed assertions about the gender of the child (Family Court of Australia 2016, 15).

As with the case of “appropriate function” meaning a cultural norm about boys standing to urinate, this case shows how an appeal to cancer risks can lead to overstated risk and inappropriate response to a risk that later appears to be grounded only in gender stereotypes, and that makes unwarranted assumptions about the will, preferences and rights of the child. Interventions justified by cancer risks need to be made using current high-quality evidence that distinguishes this rationale from rationales based on stereotypes.

For people with androgen sensitivity, it was only in 2019 that a group of clinicians has published a protocol for gonad preservation (Weidler et al. 2019).

5.3.3 Affirmation of a child’s view as to gender identity

We need to express concern about the potential for exemptions on grounds of certain purposes, such as “treatments affirming the child’s view as to their gender identity” (Chief Minister, Treasury and Economic Development Directorate 2021b). We do not favour this approach, because we wish to see a level playing field for cisgender and gender diverse people with innate variations of sex characteristics. Additionally, exemptions for gender identity affirmation can be misused. Clinical, parental and judicial views of a child’s gender identity, based on the child’s claimed preference for “female toys, clothes and activities” provided rationales for the sterilisation of a pre-school child in *Re: Carla (Medical procedure)* (Family Court of Australia 2016, paras 13–15). We believe that exemptions concerning certain medical procedures should be addressed within the “tiered model” framework that addresses scope in relation to procedures, and we consider these issues further in response to question 2, below.

5.4 Question 1d: Invalid exemptions

Psychosocial rationales, social and cultural norms for female or male bodies, gender stereotypes, technical considerations (such as a view that feminising surgery is easier than masculinising surgery) and financial considerations (such as a view that surgery can prevent a long-term need for psychological support) should all be impermissible exemptions for treatment without personal informed consent.

Claims of risk of future stigmatisation should also be excluded from consideration. This claim lacks evidence (Lee et al. 2016, 176). As expressed by the Senate Community Affairs References Committee, this argument is circular (Senate of Australia Community Affairs References Committee 2013, para. 3.128). Arguments about distress and psychological harm should not be supported if a child or adolescent is unable to freely express their will and preferences.

5.5 Question 1e: Administration

We address these issues below, in response to question 3 on oversight and advice.

5.6 Question 2: Do you have comments on, or suggestions about, adopting a tiered model for the regulation of deferrable medical interventions on intersex people?

The tiered approach appears to us to be a method of addressing scope in relation to procedures.

In an environment where harmful practices are effectively eliminated, a proportion of children, adolescents and youth with innate variations of sex characteristics will seek medical treatment, including surgical treatment and hormonal interventions. Some people with innate variations of sex characteristics already seek medical intervention of the kinds that a model bill might regulate. For these reason, legislation must give attention to healthcare access in addition to prohibition, and not assume that the only goal of proposed legislation is to prohibit or restrict treatment.

In our view, a tiered model raises concerns about neatly identifying high, medium and low-risk scenarios, and the forms of regulation applicable to each scenario.

In considering these issues, we have had regard to the national elective surgery urgency categorisation' guidelines which assign an urgency category to many common procedures. These have implications for how tiered regulations might be constructed in the ACT. The national guidelines define categories as follows:

- Category 1: Procedures that are clinically indicated within 30 days
- Category 2: Procedures that are clinically indicated within 90 days
- Category 3: Procedures that are clinically indicated within 365 days

These categories and timeframes “were chosen because they can be intuitively meaningful for clinicians” (Australian Health Ministers’ Advisory Council 2015, 5). No category exists in these guidelines for procedures that are clinically indicated only when a patient is able to determine for themselves whether or not they wish to undergo it.

The report lists some common procedures with their categorisation. Hypospadias repair is classified in category 3 (page 17 and 21) while paediatric hypospadias repair is classified as category 2. The rationales for these particular categorisations, and the differences between them, are not stated, and nor are these rationales clear from the medical literature. They seem to us to be unhelpfully grounded in undisclosed clinical preference and values.

We also note that the national scale refers to rationales for treatment that permit slippage between function and gender stereotypes of the form described earlier in this submission in relation to “appropriate” urination. The national scale refers to:

abnormal structures of the body caused by congenital defects, developmental abnormalities, trauma, infection, tumours or disease. This is usually done to improve function, but may also be done to approximate a normal appearance (Australian Health Ministers’ Advisory Council 2015, 6).

Evidence of slippage between concepts of functionality and gender stereotypes must be addressed in a legislative proposal that relies on clinical understandings of urgency, such that any references to functionality must not have any basis in gender stereotypes.

We feel that concepts of high risk, medium risk and low risk are euphemistic and fail to directly indicate applicable regulation. Our proposal instead defines tiered categories instead in relation to the minimum type of consent necessary, paying attention to the urgency or invasiveness of treatment. We propose the following categories of procedure:

- Regulated procedures where personal consent is required by the recipient
- Regulated procedures where consent is required by a representative
- Exempt procedures

While not strictly necessary within this schema, we also detail a category of prohibited procedures, where procedures take place without personal consent by the recipient.

5.6.1 Regulated procedures where personal consent is required by the recipient

There are some procedures involving changes to a person’s sex characteristics that should only ever be authorised by the person themselves. These procedures should be permissible under the following circumstances:

- Procedures where the person undergoing the treatment has provided consent, including consent via a prescribed and properly documented supported decision-making process; and
- When accompanied by a report to the oversight body, before or after the event, to ensure accountability and transparency.

In the case of minors, any application of the National Decision-Making Principles and supported decision-making should take account of the evolving capacity of a child. Procedures where children are not adequately informed, involved, and able to express, their own will, preferences and rights should be deferred until such time as they do.

A non-exhaustive list of procedures includes:

- surgical interventions, including otherwise prohibited or regulated procedures,
- treatment with sex hormones, including otherwise prohibited or regulated procedures,
- vaginal dilation.

5.6.2 Regulated procedures where consent is required by a representative

These procedures may be made by a representative supported to make a decision, such as a parent or carer, or person appointed to this role by an oversight body. These procedures may be necessary due to the age of a child or adolescent and an inability to defer treatment.

These procedures have the following characteristics:

- procedures that change a person's sex characteristics which are reversible by ceasing medical treatment or with non-invasive medical treatment; or
- procedures to manage non-urgent but high risks of cancer, where those risks are supported by high quality current data.

These procedures should be permissible under the following circumstances:

- With the consent of a parent, carer or representative following a regulated and properly documented supported decision-making process; and
- Where the will and preferences of the representative are carefully distinguished from the will, preferences and rights of the individual. To the maximum extent possible, procedures that make assumptions about the future will, preferences and rights of a person must avoid assumptions about future sexuality, gender, preferences for sexual function, or any perceived future risk of stigmatisation; and
- Where the oversight body has verified that the decision process objectively meets the standards required of a regulated decision-making process; and
- The procedure is minimally invasive and preserves all available options open for the future.

A non-exhaustive list of procedures includes:

- Fistula repair
- orchiopexy, chordee repair, and treatment for phimosis
- fertility preservation treatments, including micro-TESE (a microsurgical sperm retrieval treatment)
- gonadectomies for evidenced high risk of cancer
- treatment for evidenced repeated urinary tract infection over a long term.

5.6.3 Exempt procedures

These have the following characteristics:

- Procedures urgently necessary to preserve life or physical health; or
- procedures that preserve future options for the individual; or
- biopsies, monitoring, examinations, or testing.
- This category includes procedures that are otherwise prohibited or regulated.

This category should exclude:

- Procedures that make assumptions about the future values and preferences of a person, including their future gender, sexuality or preferences for sexual function, or any perceived future risk of stigmatisation.

These procedures should be permissible under the following circumstances:

- without prior reporting to an oversight body
- if the procedure is surgical, with reporting to an oversight body after the event for the purposes of ensuring accountability and transparency
- to the maximum extent possible under the circumstances, the procedure is minimally invasive and preserves all future options for the individual.

A non-exhaustive list of procedures includes:

- treatment for bladder or cloacal exstrophy
- treatment for salt wasting
- treatment for tumours
- puberty suppressants

5.6.4 Prohibited procedures

If the above categories are implemented in the form described, a “prohibited procedures” category is not strictly required. We include it here to promote clarity regarding procedures that, at a minimum, we expect should never take place without personal informed consent.

These procedures have the following characteristics:

- Permanent or irreversible changes to a person’s sex characteristics, or changes to a person’s sex characteristics which are reversible only with invasive medical treatment; or
- procedures that make assumptions about the future values and preferences of a person, including their future gender, sexuality or preferences for sexual function, or any perceived future risk of stigmatisation.⁴

These are procedures that should be:

- Prohibited without informed personal consent by the individual undergoing the treatment (including consent through supported decision-making).

⁴ Alternative ways of expressing this include references to psychosocial factors, gender stereotypes and social and cultural norms. The options paper refers to a potential exclusion of psychosocial rationales on page 9.

- Subject to criminal sanction if they take place without such consent, including if they take place outside the ACT. If the procedure takes place outside the ACT then the parents or carers should be held liable.

A non-exhaustive list of procedures includes:

- vaginoplasties, clitoroplasties, clitoral reduction or recession, labioplasties, vulvoplasties; treatment on a urogenital sinus (this procedure is usually associated with a vaginoplasty)
- hypospadias repairs, phalloplasties
- labial or scrotal construction, reconstruction or shaping
- gonadectomies other than as regulated above.

5.6.5 Cross-cutting issues

Documentation:

- Clinicians should confirm the documented decisions made through a supported decision-making process, including a process involving a representative before commencing with regulated treatment.
- Supporting documentation should include the nature of the procedure, the diagnosis, the age and sex assignment of the patient, the rationale for treatment and evidence of supported decision-making (such as a consent form; information on resources supplied; evidence on the purpose, risks and benefits of the treatment; human rights implications; short and long-term health management; referrals).
- A care plan, as proposed for a Victorian scheme by Equality Australia (2021) is a useful method of documenting a prescribed supported decision-making process and the related procedure(s).
- The 2016 Family Court case *Re: Carla (Medical procedure)* revealed a reliance on mis-read and obsolete data (Carpenter 2018b). Similarly, current clinical publications often rely on old studies, including studies subject to confirmation bias such as small sample studies performed by clinicians on their own patients (Hutson 2020). Medical interventions must always be evidenced using the best available current data.
- Documentation should be available to children and adolescents when they reach age 14. This age is consistent with proposed changes to the age of criminal responsibility (Chief Minister, Treasury and Economic Development Directorate 2021c). We want to avoid situations where this documentation comes as a shock through the provision of age-appropriate information (including about bodies and their potentials) and support, but peer and psychosocial support may be needed by recipients of documentation because of an unfortunate history of non-disclosure (Office of the Privacy Commissioner 2018; Lee et al. 2016, 170).

Age and surgical interventions:

- Currently and historically, many procedures that we propose to be prohibited without personal consent take place on infants and young children. For example, a 2020 paper by New South Wales paediatric endocrinologists refers to “surgical options” as a factor in sex assignment in cases of doubt (Vora and Srinivasan 2020).

In that paper, “cosmetic appearance” and sometimes culturally-determined notions of “functionality” serve as rationales for surgery, and clinical arguments disfavoured regulation, appealing to both “lack of universal interpretation of medical necessity” and lack of clinical consensus on “optimal timing” and indications (Vora and Srinivasan 2020). Children in the ACT are referred to New South Wales and Victoria for treatment.

- The oversight body should establish norms regarding the evolving capacity of the child and, potentially, a minimum age for certain otherwise prohibited procedures that should be available with supported decision-making by the person receiving treatment.

Hormonal interventions:

- In our view, treatment with sex hormones – including to kickstart puberty – should be a regulated procedure where personal consent is required. We would prefer to see no exemptions on grounds of certain purposes, such as “treatments affirming the child’s view as to their gender identity” (Chief Minister, Treasury and Economic Development Directorate 2021b), because we wish to see a level playing field for cisgender and gender diverse people with innate variations of sex characteristics.
- Additionally, such exemptions for gender identity affirmation can be misused. Clinical, parental and judicial views of a child’s gender identity, based on the child’s claimed preference for “female toys, clothes and activities” provided rationales for the sterilisation of a pre-school child in *Re: Carla (Medical procedure)* (Family Court of Australia 2016, paras 13–15).
- Sex hormone treatments in infancy should be regarded as presuming future preferences and values.
- It is consistent with the National Decision-Making Principles and respect for the evolving capacity of the child for an adolescent to be able to decide on hormonal treatment, including to kickstart puberty (as in *Re: Kaitlin* (Family Court of Australia 2017)), and including the type of hormonal intervention (i.e. feminising or masculinising treatment).

Puberty suppressants:

- These procedures should be exempt. There are many situations where puberty suppressants might form part of the treatment protocol for children with innate variations of sex characteristics, including as an alternative to surgery in situations like those described in *Re: Carla (Medical procedure)* where a pre-school child’s gonads were removed based on dubious information (Kelly and Smith 2017; Carpenter 2018a; Richards and Wisdom 2019).
- Puberty suppressants should not be considered a matter for regulation unless they are unambiguously found to have consequences for physical health that warrant regulation. We note that, if puberty suppressants are found to have consequences for one population, such as bone health in gender diverse adolescents, then they will equally have consequences for bone health in children with precocious puberty, and cisgender children with innate variations of sex characteristics.

Gender stereotypes:

- No procedures, except those with personal consent by the person undergoing treatment, should be permissible if they make pre-emptive assumptions about the future values and preferences of a person, including their future gender, sexuality or preferences for sexual function, or any perceived future risk of stigmatisation. Alternative ways of expressing this include references to psychosocial factors, gender stereotypes and social and cultural norms, building upon a statement in the options paper that refers to a potential exclusion of psychosocial rationales (Chief Minister, Treasury and Economic Development Directorate 2021b, 9).

5.7 Question 3: What suggestions do you have about what bodies should be established or utilised, how they should work, and how their work should be reported?

5.7.1 A human rights model, not a biomedical model

The current approach to treatment implements a biomedical model that seeks to prioritise biomedical considerations, but that fails to acknowledge the flawed social and cultural rationales and gender stereotypes that underpin ideas about functionality and cosmetic appearance. In our view, this model needs to be rejected. We also do not favour the replacement of the Family Court with a new court.

Several propositions in the options paper combine to suggest retention of a biomedical approach. The following two statements appear to presuppose information provision and advice by a clinical institution (first bullet below) or oversight body (second bullet below):

- *There should be people from many different professional disciplines involved in advising intersex people and their families, not just one or two medical specialisms (Chief Minister, Treasury and Economic Development Directorate 2021b, 8)*
- *Specifying the type of information that an advisory body must provide to an intersex person and their family; (Chief Minister, Treasury and Economic Development Directorate 2021b, 9)*

In contrast, the following statement appears to presuppose that a peer support organisation would not be providing these services, as families and individuals might receive a referral, but the peer support body appears to have no responsibility for service delivery:

- *[individuals and families should] be referred to peer support organisations (Chief Minister, Treasury and Economic Development Directorate 2021b, 9)*

In our view, a goal for the proposed legislation should be to provide for the role of independent Australian charities led by people with innate variations of sex characteristics in direct service delivery, including in:

- Participation in any deliberative committee, panel or other body exercising substitute decision-making authority
- Provision of human rights-affirming and other non-medical information to individuals, parents and families
- Information on human rights, psychosocial and legal issues engaged by the proposed medical treatments.

We believe that these goals are in line with norms for supported decision-making established by the UN Committee on the Rights of Persons with Disabilities, and the Australian Law Reform Commission.

Ideally, these organisations should additionally participate in clinical multidisciplinary teams and work closely with in-hospital psychosocial support structures, genetic counsellors, liaison officers and social workers.

5.7.2 Objects and goals of legislation and oversight

The objects of legislation should be to ensure that the human rights of people with innate variations of sex characteristics are protected and fulfilled, including through:

- the elimination of harmful practices on people with innate variations of sex characteristics in medical settings
- protection of the rights to bodily integrity, physical autonomy and self-determination of people with innate variations of sex characteristics in medical settings
- regulation of medical treatment modifying sex characteristics without personal consent
- to the maximum extent possible, provide for supported decision-making by individuals and their parents and carers, in line with National Decision-Making Principles
- protect the right to access treatment with consent.

The final proposed object, on the right to access treatment with appropriate consent, seeks to address fears raised with us about any potential for difficulties in accessing regulated treatments.

These objects should govern the operation of the oversight body, and any work to develop standards or norms regarding treatment and access to treatment.

5.7.3 Oversight body role

The oversight body should regulate and oversee the provision of supported decision-making, including decision-making by individuals and by representatives. The oversight body

must ensure that providers meet the standards set in the National Decision-Making Principles; these Principles ensure attention to safeguards that avoid coercion. The oversight body must ensure provision of human rights-affirming non-medical information in addition to biomedical information. The oversight body must verify that a decision affecting minors objectively meets the standards required of a regulated decision-making process; the oversight body will carry the liability for those decisions.

The oversight body should be empowered to develop, or collaborate in the development of, norms and standards regarding regulated procedures and supported decision-making. These should have regard to the evolving capacity of the child. The body might also have a useful role in directing resources to professionals and charities providing support for individuals, families and carers, and in directing funds for the development of resources.

In any alternative scenario where the oversight body is not responsible for regulating and overseeing the provision of supported decision-making, the oversight body must develop and issue guidelines on implementing supported decision-making, and clinicians and hospitals should refer to these when establishing internal systems in order to meet the requirements under the legislation. We prefer a support infrastructure independent of clinicians and hospitals.

Substitute decision-making should be exercised only in the last resort, and all such decisions should further the human rights objects of the legislation. Where necessary, substitute decision-making authority should be exercised by a small committee or panel, appointed for the purpose by the governing committee oversight body. The composition of this committee or panel should mirror that of the governing committee. An individual, parent or carer, or clinician should be able to appeal to the full governing committee. Decisions of the full governing body should be able to be appealed for judicial review.

5.7.4 Oversight body structure and location

The oversight body should have a governing committee comprising one third human rights expert(s), one third healthcare practitioner(s) including a mental health professional,⁵ and one third representative(s) of Australian independent charity/charities led by people with innate variations of sex characteristics including a parent. A governing committee of nine members would be appropriate.

These members might be appointed by a Minister for a period of 3 or 4 years. Members should be remunerated for their work, have access to sufficient psychosocial supports, and receive a limitation on their personal liability. We suggest that members need not be resident in the ACT, though a majority must do so.

In line with our comments on ensuring a human rights approach, we recommend that the oversight body should be chaired by a human rights expert, such as a human rights commissioner, and hosted by the Human Rights Commission.

⁵ We note that medical doctors, bioethicists and psychologists are healthcare practitioners

The oversight body should seek to make decisions by consensus. If this is not achievable, then at least one respondent from each of the three types of representative should be required to agree. Decisions and any declarations of dissent should be recorded and periodically reported.

5.7.5 Accountability and transparency

Given that the proposed population scope of the legislation is narrow, we believe that it is possible to document every procedure affecting the population resident in the ACT, including procedures that arise from referrals out of the jurisdiction. Clinicians and any multidisciplinary team should have the obligation of providing supporting documentation to the oversight body in cases where personal informed consent is asserted by a patient. Penalties for non-compliance should apply.

The oversight body should ensure transparency and accountability in the conduct of supported decision-making processes.

The oversight body should periodic reports presenting anonymised summary information on all cases and procedures reported to the body, and on the operation of the body itself. This data should be readily available to the diverse stakeholders, including medical practitioners, individuals and families, community groups and human rights institutions.

5.8 Question 4: Additional comments

Several areas of action that are important to IHRA are not yet considered in proposals for law reform. We propose that the ACT government:

Statute of limitations:

- Individuals subject to treatment without their personal consent may be unable to seek recourse outside a 6 year period (12 years in the case of accidents giving rise to an injury) after an event specified in Section 30B of the Limitation Act 1985 (ACT). Additionally, parental or carer first knowledge of an action is taken to comprise sufficient knowledge of an action. Section 36(6) makes the period of limitation discretionary, but this gives inadequate protection. We recommend that parental knowledge of an action should not limit a child's future rights. The 6-year time limitation should be extended in respect of medical interventions on an individual's sex characteristics.

Review:

- The legislation should be subject to a review at the five year stage to ensure efficacy.

Jurisdiction shopping:

- Establish a criminal penalty for jurisdiction shopping; this is necessary to make any reform effective, given the role of clinicians in other jurisdictions in treating children in the ACT. This is consistent with provisions in Section 75 of the Crimes Act 1990 (ACT) prohibiting “Removal of child from ACT for genital mutilation”, where genital mutilation refers to female genital mutilation.
- In our view, the penalty for removal of a child from the ACT for genital mutilation (Section 75 of the Crimes Act) should be harmonised with the penalty for performing the practice (Section 74).

Redress:

- We recommend that passage of a bill be accompanied by a formal and unambiguous apology for practices that exist to the present time.
- An apology should be accompanied by a commitment to action to provide redress for those who have experienced harm in, or following referral from, the ACT (Peck and Feder 2017).

Education and reducing social coercion:

- Commit to resourcing for education about the existence of intersex people (Brömdal et al. 2020; Zavros-Orr 2020), with the goals of promoting capacities for informed decision-making, and promoting awareness amongst parents and carers, prospective parents and carers, and community members more broadly.
- Commit to providing human rights-affirming material on innate variations in sex characteristics in schools.
- These commitments are intended to provide safeguards to reduce the potential for coercion in social and community settings.

IHRA would welcome any opportunity to assist the ACT government further with the development and passage of such a bill.

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