

**2023**

**THE LEGISLATIVE ASSEMBLY FOR THE  
AUSTRALIAN CAPITAL TERRITORY**

**VARIATION IN SEX CHARACTERISTICS (RESTRICTED MEDICAL  
TREATMENT) BILL 2023**

**EXPLANATORY STATEMENT  
and  
HUMAN RIGHTS COMPATIBILITY STATEMENT  
(*Human Rights Act 2004, s 37*)**

**Presented by  
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# VARIATION IN SEX CHARACTERISTICS (RESTRICTED MEDICAL TREATMENT) BILL 2023

The Bill is a Significant Bill. Significant Bills are bills that have been assessed as likely to have significant engagement of human rights and require more detailed reasoning in relation to compatibility with the *Human Rights Act 2004*.

## OVERVIEW OF THE BILL

This Bill is a key element of the ACT Government's commitment to reform how treatment and support is provided to people who have variations in sex characteristics. In the Capital of Equality First Action Plan 2019-2021,<sup>1</sup> the Government committed to collaborating with people with variations in sex characteristics, human rights organisations and healthcare professionals to reform how treatment and support is provided to people who have variations in sex characteristics.

The Bill responds to the needs of people with variations in sex characteristics to not be subject to harm through inappropriate medical interventions, and to uphold their ability to make their own decisions about non-essential medical treatments that affect their bodies. The Bill represents part of the Government's response to the Darlington Statement, a joint consensus statement issued by Australian and Aotearoa/New Zealand intersex organisations and independent advocates, in March 2017.<sup>2</sup> It is also a response consistent with recommendations of the Senate Community Affairs References Committee,<sup>3</sup> the Australian Human Rights Commission,<sup>4</sup> the UN Committee on the Elimination of Discrimination against Women,<sup>5</sup> the UN Committee

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<sup>1</sup> ACT Government, 2019, *Capital of Equality First Action Plan 2019-2021*, <https://www.cmtedd.act.gov.au/policystrategic/the-office-of-lgbtqi-affairs/capital-of-equality-act-government-lgbtqi-strategy>

<sup>2</sup> Androgen Insensitivity Syndrome Support Group Australia, Intersex Trust Aotearoa New Zealand, Organisation Intersex International Australia and others, 2017, *Darlington Statement*, <https://darlington.org.au/statement/>

<sup>3</sup> Senate Community Affairs Committees, 2013, *Involuntary or coerced sterilisation of intersex people in Australia (second report)*, [https://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Involuntary\\_Sterilisation/Sec\\_Report/index](https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation/Sec_Report/index)

<sup>4</sup> Australian Human Rights Commission, 2021, *Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics*, <https://humanrights.gov.au/intersex-report-2021#bIXcN>

<sup>5</sup> United Nations Committee on the Elimination of Discrimination against Women, 2018, *Concluding observations on the eighth periodic report of Australia*, CEDAW/C/AUS/CO/8

on the Rights of the Child,<sup>6</sup> and the Committee on the Convention on the Rights of Persons with Disability.<sup>7</sup>

The Bill will establish a new process to be applied when an irreversible medical treatment for people with variations in sex characteristics is being considered. Its effect will be to permit these interventions only when they meet criteria set out in the Bill.

The Bill will also support the provision of information, advice and psychological and peer support to people with variations in sex characteristics and their families.

### **Key terms in this field and in the Bill**

People who have ‘variations in sex characteristics’, or are intersex, are born with sex characteristics (such as genitals, gonads or chromosome patterns) that do not fit typical binary notions of male or female. The Bill refers to variations in sex characteristics, but it is recognised that a range of terms are used by individuals and organisations that represent or provide services to these populations. Some prefer to refer to the individual variation in sex characteristics they have (for example, congenital adrenal hyperplasia or CAH), or to refer to these variations as differences of sex development or disorders of sex development (DSD). For the purpose of the reform of which this Bill is part, these terms are treated as interchangeable and are about a person’s bodily diversity. They are not descriptions of a person’s identity, and specifically do not relate to a person’s gender or sexuality.

The purpose of the Bill is primarily to provide decision-making support and oversight for certain critical medical treatment decisions that are made by parents for their children, however the terms ‘parent’ and ‘child’ mostly are not used in the Bill, for reasons set out here.

In this Bill, a ‘prescribed person’ means a person to whom the Bill’s protections apply. In the great majority of cases this will be a child who is not yet able to make a legal decision themselves about their medical treatment. However, in a small number of cases, a prescribed person may be an adult under a guardianship order.

In this Bill there is frequent reference to the ‘decision-makers’ for a prescribed person. Again, in the great majority of cases this will mean a parent or parents. However, in some cases it may be another person exercising parental responsibility under the *Children and Young People Act 2008*, division 1.3.2. In addition, in the

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<sup>6</sup> United Nations Committee on the Rights of the Child, November 2019, *Concluding observations on the combined fifth and sixth periodic reports of Australia*, CRC/C/AUS/CO/5-6.

<sup>7</sup> United Nations Committee on the Convention on the Rights of Persons with Disability (CRPD), September 2019, *Concluding Observations: UN Report on Australia’s Review of the CRPD*, CRPD/C/AUS/CO/2-3.

small number of cases where the prescribed person is an adult, it will be the person's guardian.

The Bill establishes a new statutory body, the 'Restricted Medical Treatment Assessment Board' (the board). From the board, individual 'assessment committees' are drawn, being established whenever an assessment decision is to be made. If a decision of an assessment committee is being reviewed, usually at the request of someone who applied for a decision, this is done by a newly constituted committee, called an 'internal review committee'.

### **Statutory oversight to manage risks to the rights of people with variations in sex characteristics**

The Bill provides assurance that all decisions that trigger irreversible medical treatments affecting the sex characteristics of prescribed persons with variations in sex characteristics uphold the rights of those people.

This Bill is designed to address known areas of risk to these rights that have been identified by human rights bodies and advocates with lived experience of variations in sex characteristics. These human rights matters were explored in detail by the Australian Human Rights Commission (AHRC) in its 2021 report *Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics*. Following its review, the AHRC set out five principles it proposed should be applied to decision-making for people with variations in sex characteristics. These principles underlie this Bill:

- *Bodily integrity principle*: All people have the right to autonomy and bodily integrity. Medical interventions on people without their personal consent have the potential to seriously infringe these rights.
- *Children's agency principle*: Children and young people have the right to express their views in relation to decisions that affect them, and those views must be given due weight in accordance with their age and maturity. The ability of children to consent to medical interventions generally increases as they grow older. Children and young people who are able to understand fully the nature and consequences of proposed medical interventions should be able to make their own decisions about whether those interventions proceed.
- *Precautionary principle*: Where safe to do so, medical interventions to modify the sex characteristics of a child born with variations in sex characteristics should be deferred until a time when the child is able to make their own decisions about what happens to their body.
- *Medical necessity principle*: In some cases, to protect the child's rights to life or health, it may be medically necessary for a medical intervention to modify the sex characteristics of a child born with variations in sex characteristics to occur before a child can make their own decision. An intervention will be medically necessary if it is required urgently to avoid serious harm to the child.

- *Independent oversight principle*: Given the risk of making a wrong decision, decisions about whether a medical intervention to modify the sex characteristics of a child born with variations in sex characteristics is medically necessary should be subject to effective independent oversight.

These principles are given effect through both the structure of the board, and the decision criteria that it applies.

To give effect to the principles of independent oversight, bodily integrity, children's agency, and precaution, the Bill establishes statutory oversight of key medical decisions that are designed to uphold a person's human dignity and right to physical integrity. The Bill supports these objectives through the requirement that committees assess whether there is sufficient evidence:

- That the person for whom a treatment is being proposed genuinely is not able to make a decision for themselves (section 16(a));
- That adequate information is being provided to prescribed persons and their families about treatment, including the possibility of deferring or not undertaking treatment (section 16(b));
- That information is being provided to a prescribed person with support to understand it, where needed (section 16(c));
- That a prescribed person has been given support to express their wishes, and these have been appropriately considered (sections 14(a) and 16(e)).

The Bill also supports these principles by requiring the committee to consider whether a treatment can safely be deferred, and whether the proposed treatment places as few restrictions as possible on the ability to make future decisions about the person's sex characteristics (section 13).

The new statutory oversight scheme gives effect to the medical necessity principle by not restricting treatment that meets the definition of 'urgent restricted medical treatment' in the Bill. To support implementation of the medical necessity principle, the Bill also gives additional guidance to the board and its committees. This relates particularly to ensuring that the right not to be subject to medical treatment without free consent<sup>8</sup> is upheld without discrimination on the basis that a person has a variation in sex characteristics.<sup>9</sup>

The protection of oversight of key decisions addressing harmful treatment practices, together with increased psychosocial supports for individuals, represent a special measure to uphold a person's right to be free from discrimination.<sup>10</sup> It will also

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<sup>8</sup> *Human Rights Act 2004*, s.10.

<sup>9</sup> *Human Rights Act 2004*, s.8; *Discrimination Act 1991*, s.7.

<sup>10</sup> *Human Rights Act 2004*, s.8; *Discrimination Act 1991*, s.7.

support the right to be free from unnecessary medical treatment without personal consent.<sup>11</sup> The Bill will work in parallel with psychosocial services for families, peer support, education and awareness-raising.

### **The main features of the Bill**

The Bill establishes a new process of statutory decision-making when a ‘restricted medical treatment’ is proposed for a ‘prescribed person’ or people, who have ‘variations in sex characteristics’. It will authorise these treatments where criteria are fulfilled that are set out in the Bill.

#### *Variation in sex characteristics*

The Bill defines a variation in sex characteristics as a congenital condition that involves atypical sex characteristics. ‘Sex characteristics’ means:

- (a) a person’s chromosomal, gonadal or anatomical sex; and
- (b) includes—
  - (i) the person’s hormones that are related to sex; and
  - (ii) the sexual and reproductive parts of the person’s anatomy; and
  - (iii) the person’s secondary physical features emerging as a result of puberty.

This definition has drawn on definitions used elsewhere, including in medical literature,<sup>12</sup> and is designed to provide legal clarity.

The Bill applies to all congenital variations in sex characteristics, regardless of a formal diagnosis. To provide further certainty about what the law covers, the definition will support the creation, by regulation, of a list of named variations that are included. The regulations will also contain a separate list of a small number of conditions or variations that the authorisation process in the Bill will not apply to.

#### *Restricted medical treatment*

A ‘restricted medical treatment’ is a surgical or medical procedure or treatment (including the prescription or administration of a drug) that permanently changes the person’s sex characteristics, or which makes changes to the person’s sex

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<sup>11</sup> *Human Rights Act 2004*, s.10(2).

<sup>12</sup> See, for example, Sonia R. Grover, Chloe A. Hanna, and Michele A. O’Connell, 2020, ‘Introduction: Changing Landscapes’, in John M. Hutson, Sonia R. Grover, Michele A. O’Connell, Aurore Bouty, Chloe A. Hanna, (Editors), *Disorders/Differences of Sex Development: An Integrated Approach to Management*, Second Edition, Springer, pp.1-2; Hughes, I A, C Houk, S F Ahmed, P A Lee, and LWPES/ESPE Consensus Group. 2006. ‘Consensus Statement on Management of Intersex Disorders’. *Archives of Disease in Childhood* 91: 554–63.

characteristics that are only reversible with a further medical procedure or treatment. Examples of the kinds of treatments the Bill will apply to include labiaplasty, phalloplasty, or gonadectomy. It also includes those hormone treatments that cause permanent changes to a person's sex characteristics, such as breast growth or change in vocal pitch. These treatments are included because of experiences reported during community consultations by people with variations in sex characteristics of having received hormone treatments against their will in childhood or adolescence.

Restricted medical treatment will not include circumcision of the penis. Circumcision of the penis has been excluded for several reasons:

- First, this Bill applies only to people who have a variation in sex characteristics. If circumcision of the penis were not exempted, this would mean people without a variation in sex characteristics could be circumcised, while those with a variation could not, despite there not necessarily being an underlying difference in the health circumstances between those two groups.
- Second, the rationales for circumcision of the penis compared to the medical treatments this Bill is seeking to limit are different. The rationales for non-essential restricted medical treatments on people with variations in sex characteristics are underpinned by normative ideas about how bodies should appear and function, and assumptions about the effects of growing up with non-normative sex characteristics. Circumcision of the penis is generally underpinned by parental beliefs about hygiene, family tradition and/or religious beliefs.
- Third, because there is a religious element to why some people seek to circumcise their children, prohibiting circumcision would involve a different consideration of human rights relating to bodily autonomy and freedom of religious practices. This sits outside the scope of the project.

### *Prescribed person*

The Bill is designed to protect the rights of people who lack the capacity to make their own decisions about treatments to their bodies. When they are able to make decisions for themselves, they no longer need a statutory body intervening in their care. A prescribed person may be a child who does not yet have the maturity to make a legal decision or express views and preferences. However, they will often be able to express views and preferences, which will be pivotal in decision-making for them. A prescribed person may also be an adult who has been assessed to not have the legal capacity to make some health decisions, and is under guardianship to assist them with those decisions.

### *Scope*

The scope of the authorisation process in the Bill will be limited. The Bill will not be engaged for medical treatment where:

- The treatment will not permanently change the person’s sex characteristics; or
- The treatment does not affect their sex characteristics; or
- The person has capacity to make their own decisions about the medical procedure.

If a medical treatment proposed for a person with variations in sex characteristics does not meet any of those conditions, then it will be a restricted medical treatment.

The Bill also recognises that some medical treatments must be performed urgently to preserve the health of a person with a variation in sex characteristics. These will be allowed, if they are:

treatment required to be undertaken urgently to—

- (a) save a prescribed person’s life; or
- (b) prevent serious damage to the person’s health; or
- (c) prevent the person from suffering or continuing to suffer significant pain.

If something is a restricted medical treatment and is not urgent, then before it can be undertaken, it must be covered by a treatment plan that is approved by a new statutory body, the Restricted Medical Treatment Assessment Board, established under Part 5 of the Bill. The process will be similar to how some mental health treatments are currently administered under the *Mental Health Act 2015*.

The board will be made up of individuals with expertise or experience in five different categories: human rights; medicine; ethics; lived experience of variation in sex characteristics; and provision of psychosocial support. Each time a decision is required, an assessment committee will be created, made up of one member from each of the five categories of expertise from the board’s membership. In the case of the medicine category, there will be additional guidance in subordinate legislation to support recruitment of members from relevant medical specialities.

### *Treatment plans*

There will be two types of treatment plans: individual, and general.

An individual treatment plan will be a plan approved by a committee for a particular person (section 26). A proposed individual plan can be submitted by treating doctors or by parents or guardians, with the input of the person affected, if they are able to communicate their wishes (section 11(2)). The proposed treatment plan will need to set out a range of information and evidence. Some of this will be specified in the legislation; some may be requested by the committee (sections 11(3); 19). If the individual treatment plan is approved, then treatment can occur consistent with the plan.



A general treatment plan will be a plan approved by a committee for a restricted medical treatment to be undertaken on a class of prescribed people (section 11(1)(a)). These could be, for example, all prescribed people with a particular variation in sex characteristics, or all prescribed people who have a variation in sex characteristics and are proposed to receive a particular type of restricted medical treatment. It is expected that these applications will usually occur for the more common variations in sex characteristics, and where there is a strong evidence base for treatment that should commence during childhood. It is expected that in most cases general treatment plan applications will come from groups of health professionals or specialist associations, or from an association of people with variations in sex characteristics. General plans will not refer to a specific individual, although each individual will still need to be appropriately involved in decision-making that occurs under a general plan.

Timeliness can be important to care decisions, so the legislation will require that a committee must be convened within a reasonable time frame, at most, 14 days after the application is received (section 12). In practice, if an applicant notifies the board that there is a reason they need faster consideration, it is expected that the board will be responsive to that.

The consideration and approval of proposed general treatment plans will include a period of consultation, including with health professions and community organisations (section 21). Once a general treatment plan has been approved by a committee it will be notified on the legislation register and accessible to health professionals and families. Health professionals can then undertake a medical treatment of the type covered by a general plan, without needing an application for an individual medical treatment plan.

In considering either a general or individual treatment plan, the legislation will require committees to approve plans where all the necessary criteria are met (sections 13 to 16). Their role is not to determine the best treatment for an individual, but to check that any proposed treatments will be consistent with the criteria intended to protect people with variations in sex characteristics.

Individual treatment plans are expected to be approved for a period of up to three years – it will be up to the committee, drawing on information provided in the application and all other information available to them, to determine what is the right time period for that individual's plan (Section 26(4)). General plans are expected to be approved for a fixed period of five years and can be reviewed and renewed after this time (Section 23(4)). A general treatment plan can also be reviewed at any stage if the board becomes concerned that it no longer meets the criteria for a treatment plan, for example, because of changes in the medical evidence available regarding benefits or harms (section 24).

## *Decision criteria*

The Bill provides decision-making criteria for an assessment committee when considering whether to approve a treatment plan. The committees will only approve plans once satisfied there is sufficient evidence to satisfy the criteria.

Underpinning the criteria is the core principle that whenever possible, a person with a variation in sex characteristics should make their own decisions about permanent medical treatments that affect their bodies. When a restricted medical treatment is proposed, the committee needs to be satisfied that undertaking the treatment, rather than deferring it, is needed to avoid significant harm to the person (section 13(1)(a)). It will look at whether the treatment proposed is the one that keeps the most options open for future treatment, while addressing the significant harm (section 13(1)(c)). This will require the committee to consider what alternatives might be available, and be satisfied that the one in the proposed treatment plan is no more restrictive of the ability to make a decision about a prescribed person's sex characteristics in the future than any alternative treatment option.

It is important that prescribed persons are supported to the greatest extent possible to understand their treatments, and treatment choices, and to participate as far as possible in decision-making. Section 16 includes requirements that prescribed persons and their decision-makers are provided with information in a form they can understand; and that prescribed persons are given support to understand the information, consistent with their cognitive ability. The wishes of prescribed persons who are children (section 14(a)), and adults (section 15(a)), are required to be considered in the decision-making process.

The criteria include a requirement about how the assessment committee consider arguments put to them that a treatment needs to be undertaken to reduce discrimination or stigmatisation or a perceived risk of discrimination or stigmatisation. As set out in detail in the section on human rights compatibility, below, there is no evidence that treatment for this purpose is effective, while it presents a significant human rights risk, when a person is not making a decision for themselves. The Bill requires the assessment committee to set aside evidence put to it that such a treatment should be performed on a child. In the case of an adult who lacks decision-making capacity, an assessment committee must likewise set evidence of this kind aside, with the exception of when it is satisfied the person has communicated a wish to have the treatment undertaken for such a purpose. In that case, the assessment committee can consider the evidence; however, it must still only give approval if the other criteria (described above) have also been met.

There are two reasons for the difference in approach between children and adults. First, while the government was presented with a strong evidence base relating to the risks of undertaking treatment for these purposes on children, that evidence base was not as strong for adults. This is primarily because there are relatively few treatments being performed on adults who lack legal decision-making capacity: the

population of people with a variation in sex characteristics is small, and the fraction who are adults under guardianship or similar, extremely small. In the circumstances where evidence was sparse, it was not clear that the condition should be as absolute as it is for children.

The second reason is the difference between the objectives for upholding the rights of people under the *Convention on the Rights of the Child*, and the *Convention on the Rights of Persons with Disabilities*. The goal for adults with disabilities is for them, to the maximum possible extent, to be supported to make their own decisions. This includes decisions that might not be considered optimal but which mean they are freely exercising the same choices as other adults. The Bill seeks to work toward this objective by both requiring the committee to be satisfied that adequate support has been provided to a prescribed person to understand information about treatment and to communicate their wishes (section 16(c) and (e)), and to be satisfied that those wishes have been communicated freely and not, for example, under the influence of someone else (section 16(e)(i)). If, in all these circumstances, the prescribed person still expresses reasons for wanting a treatment, and those reasons relate to discrimination or stigmatisation, the committee can take this into account in determining whether they would experience significant harm if the treatment plan were to be refused.

#### *Decision review mechanisms*

If an applicant for a treatment plan – whether individual or general – is not satisfied with the committee’s decision, the Bill contains two levels of review. In the first instance, the applicant can seek internal review (sections 36-40). In this case, a fresh committee of five different members of the board is convened to review the decision and decide whether to confirm, vary, or set aside the internally reviewable decision. If the applicant is still not satisfied, there will be an avenue of review to the ACT Civil and Administrative Tribunal (ACAT) (sections 41-42). In both cases, the intention is to provide easily accessible pathways for decision review, that do not require going to court.

#### *Offences*

The regulatory requirements in the Bill are supported through the creation of two offences.

The first offence – undertaking restricted medical treatment without approval (section 27) – applies to a person undertaking a restricted medical treatment on a prescribed person unless it is covered by an approved treatment plan, except if the treatment is urgent.

The second offence – to authorise or arrange unapproved restricted medical treatment (section 28) – makes it an offence for someone to deliberately arrange or authorise for restricted medical treatment to be undertaken on a prescribed person, even though they know that authorisation is required. Deliberately organising to take

someone outside the ACT to attempt to avoid the scheme would be an example of this. This offence sets a high burden of proof on the prosecution, who must demonstrate that the defendant knew that the restricted medical treatment must not be undertaken on the prescribed person. This is to ensure that it does not capture people who were not aware that the treatments are restricted.

Offence provisions are the normal mechanism for supporting compliance with a law. The adverse effects of restricted medical interventions, performed for inappropriate reasons or without adequate care, on people with variations in sex characteristics, can be extremely serious. Some of the outcomes that have been evidenced include lifelong psychological or physical pain, and unnecessary and permanent loss of fertility. The Bill ensures there will be consequences for deliberate and reckless disregard for laws designed to protect vulnerable people.

The penalty provision that accompanies an offence sets the maximum penalty that can ever be applied. It does not represent a typical penalty: instead, it is for “the most serious examples of an offence committed by the worst type of offender”.<sup>13</sup> This would include, for example, the worst possible consequences for the victim. This law reform is dealing with actions that, in the worst circumstances, have been documented to have extreme, lifelong adverse effects on the victim. The penalties have been drafted with careful reference to other offences across ACT and national laws, including other offences in laws governing health professionals. These include the penalties in offences concerning:

- Importing or supplying medical devices that are not approved, if the use of the device would, or was likely to, cause harm to a person;<sup>14</sup>
- Advertising of therapeutic goods in breach of legislative requirements, if the use of the advertised goods could, or was likely to, cause harm to a person;<sup>15</sup>
- Performing, or offering to perform, a cosmetic procedure on a child, unless in accordance with certain exceptions;<sup>16</sup>
- Performing a sexuality or gender identity conversion practice on another person (the recipient); and the recipient is a protected person;<sup>17</sup> and

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<sup>13</sup> Victorian Sentencing Advisory Council, Maximum penalties, <https://www.sentencingcouncil.vic.gov.au/about-sentencing/maximum-penalties>. See also Queensland Sentencing Advisory Council, Maximum penalties, <https://www.sentencingcouncil.qld.gov.au/about-sentencing/maximum-sentences>

<sup>14</sup> *Therapeutic Goods Act 1989* (Cth), s.41MA.

<sup>15</sup> *Therapeutic Goods Act 1989* (Cth), s.42DL.

<sup>16</sup> *Public Health Act 2005* (Qld), s.213B.

<sup>17</sup> *Sexuality and Gender Identity Conversion Practices Act 2020*, s.8.

- Performing psychiatric surgery on a person and the doctor has no approval to do so from the chief psychiatrist, or the doctor has been told that the person refuses to have the surgery.<sup>18</sup>

### *Reporting requirements*

Something that both health professionals and community advocates have sought is better information about what treatments are being undertaken on people with variations in sex characteristics. The Bill (section 43) will require treating medical professionals to report to the board de-identified data about treatments performed under a treatment plan. It will also require reporting of treatments that are undertaken under the exemption for urgent medical treatment, to allow the board to monitor the use of that exemption.

### *Privacy protections*

There are a range of protections in the Bill and in other ACT laws that preserve the privacy of prescribed persons. When a committee is consulting outside expertise to inform its decision about an individual treatment plan, they are not permitted to release the identity of the prescribed person without the permission of that person's decision-maker (section 18(3)). Similarly, when publishing submissions received during community consultations on a draft general treatment plan, it will only publish a submission that identifies a prescribed person when publication is consistent with that person's will and preferences (section 22(3)). When publishing its annual report, the board is not permitted to include information that identifies a prescribed person or a decision-maker for the prescribed person, or that would allow such persons to be identified (section 44(2)). Records held by the board that contain personal information will be covered by the *Health Records (Privacy and Access) Act 1997* and the Privacy Principles in that Act.

### *Mechanisms for flexibility and review*

This reform is leading nationally and internationally, and needs mechanisms built in for adaptation and review. These include:

- Accessible internal and external decision review pathways without applicants having to resort to the courts (Part 6);
- Discretion for the board to initiate a review of a general treatment plan, where concerns emerge that it may no longer meet the criteria set out in the Bill (section 24);
- Capacity for Ministers, following consultation, to make regulations that move individual variations in sex characteristics within, or outside the authorisation scheme in the Bill (section 7(1)(b) and (c)); and

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<sup>18</sup> *Mental Health Act 2015*, s.168.

- A requirement that a review of the operation of the legislation be conducted after two years (section 47).

### *Staged introduction*

The introduction of the scheme in the Bill is being carefully staged through a two-step commencement process (section 2). This has been designed to avoid disruption to care of existing patients as well as to ensure care decisions can be made for new patients, including babies born during the period when the Bill is being considered and has not yet commenced. This requires training of the healthcare workforce ahead of the legislation taking effect. It also requires a system that will ensure treatment plans are ready to support care decisions when the Bill's provisions become mandatory. This is being achieved by staging commencement to allow a period of six months from when the bill is passed to when the Restricted Medical Treatment Assessment Board is established and can operate. There will then be a further period of 12 months in which the board will consider applications for treatment plans before the regulatory provisions requiring authorisation of restricted medical treatments take effect.

### *Matters the Bill does not alter*

There are several things that this Bill does *not* do:

- It does not regulate decisions where the person themselves is consenting to the treatment, including a legally consenting child. The capacity to consent is covered by existing common law, and is unchanged by this reform.
- It does not replace parental decision-making. Parents will be able to choose and consent to any treatment that the committees have agreed should be available. Parents will be able to be the applicants for treatments to be approved. Parents will remain the people who consent to a treatment, where a child is not providing that consent themselves.
- It does not displace the role of multi-disciplinary teams (MDTs). MDTs are groups of specialist professionals brought together in a tertiary healthcare setting to consider cases and review treatment actions proposed by an individual's treating doctor or treating team. Current best practice recommends MDT review of complex management decisions affecting people with variations in sex characteristics.<sup>19</sup> The government supports referral to MDTs, and advice from MDTs would be among the information a committee would consider when making decisions.

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<sup>19</sup> See, for example, Australia and New Zealand Society for Paediatric Endocrinology and Diabetes, Position Statement of the Australia and New Zealand Society for Paediatric Endocrinology and Diabetes on the clinical care of children with DSD, 27 June 2022, [https://media.anzsped.org/2023/02/22184237/22\\_06-V1.1-DSD-Position-Statement-clean.pdf](https://media.anzsped.org/2023/02/22184237/22_06-V1.1-DSD-Position-Statement-clean.pdf)

## CONSULTATION ON THE PROPOSED APPROACH

In 2019, the government committed in the Capital of Equality First Action Plan to collaborate with intersex people, human rights organisations and healthcare professionals to form a plan on how prohibition of deferrable medical interventions on intersex people could operate in Canberra.

Variations in sex characteristics affect a small and dispersed segment of the population, meaning there is a limited number of stakeholder organisations working in this field. These were identified and approached during key consultation stages. These organisations comprised:

- Intersex advocacy organisations
- Syndrome-specific support groups
- Health professional representative organisations and colleges
- Specialist medical teams
- Human rights and/or child and family welfare organisations
- LGBTIQ+ rights and advocacy organisations
- Academic researchers

Three phases of community and expert stakeholder consultation occurred. After each phase, the government published a listening report summarising all stakeholder feedback.<sup>20</sup>

In December 2020, the Government released a discussion paper and received submissions from across the categories of stakeholders. In April 2021, the Government commissioned a legal issues workshop to better understand the legal factors that may be relevant in designing the regulation of deferrable medical

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<sup>20</sup> ACT Government, Chief Minister, Treasury and Economic Development Directorate, April 2021, Prohibition of deferrable medical interventions on intersex people: Listening report on submissions received, [https://www.cmtedd.act.gov.au/\\_data/assets/pdf\\_file/0014/2004107/Discussion-Paper-Listening-Report.pdf](https://www.cmtedd.act.gov.au/_data/assets/pdf_file/0014/2004107/Discussion-Paper-Listening-Report.pdf); ACT Government, Chief Minister, Treasury and Economic Development Directorate, October 2021, Protecting the rights of intersex people in medical settings: Listening report on submissions received about regulatory options, [https://www.cmtedd.act.gov.au/\\_data/assets/pdf\\_file/0008/2004110/Options-Paper-Listening-Report.pdf](https://www.cmtedd.act.gov.au/_data/assets/pdf_file/0008/2004110/Options-Paper-Listening-Report.pdf); ACT Government, Chief Minister, Treasury and Economic Development Directorate, August 2022, Draft legislation to protect the rights of people with variations in sex characteristics in medical settings: Listening report on submissions received, [https://www.cmtedd.act.gov.au/\\_data/assets/pdf\\_file/0009/2065662/Listening-Report\\_Variations-in-Sex-Characteristics-Bill.pdf](https://www.cmtedd.act.gov.au/_data/assets/pdf_file/0009/2065662/Listening-Report_Variations-in-Sex-Characteristics-Bill.pdf)

interventions on intersex people. A report summarising those workshop discussions, prepared by Equality Australia, was published.<sup>21</sup>

Three major policy conclusions were reached as a result of the first phase of research and consultation. These were:

- The need for additional psychosocial and peer supports to be provided to people with variations in sex characteristics and their families if there was to be regulatory oversight.
- A decision not to seek to prohibit outright any medical interventions (which had been the initial approach considered).
- The necessity for legislative action in order to meet the policy's goals.

In June-July 2021, the Government released an options paper for stakeholder feedback. Whereas the first paper sought input on issues generally, this second sought responses around implementation options. Based on all of the sources of information, including community submissions on the options paper, research and expert input, the government prepared draft legislation and released it for community consultation in May-July 2022. This process invited people to make either written submissions or fill out an online questionnaire. This public consultation gathered more than 70 written responses. In addition, four dedicated workshops were held for:

- human rights and legal experts,
- intersex advocates and people with lived experience,
- local clinical and healthcare workers, and
- medical colleges and professional associations.

A listening report summarising the feedback and perspectives received during the consultation was published.<sup>22</sup>

The third phase of consultations were instrumental in shaping the Bill in several areas:

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<sup>21</sup> Equality Australia, April 2021, Report to the ACT Government: Towards a prohibition on deferrable medical interventions on intersex people: Report on the outcomes of the legal workshop on how a prohibition could operate in the Australian Capital Territory, [https://www.cmtedd.act.gov.au/\\_data/assets/pdf\\_file/0011/1764308/Final-report-on-legal-workshop.pdf](https://www.cmtedd.act.gov.au/_data/assets/pdf_file/0011/1764308/Final-report-on-legal-workshop.pdf)

<sup>22</sup> ACT Government, Chief Minister, Treasury and Economic Development Directorate, August 2022, Draft legislation to protect the rights of people with variations in sex characteristics in medical settings: Listening report on submissions received, [https://www.cmtedd.act.gov.au/\\_data/assets/pdf\\_file/0009/2065662/Listening-Report\\_Variations-in-Sex-Characteristics-Bill.pdf](https://www.cmtedd.act.gov.au/_data/assets/pdf_file/0009/2065662/Listening-Report_Variations-in-Sex-Characteristics-Bill.pdf)



- The way ‘variations in sex characteristics’ is defined, and the system of examples and exclusions by regulation (section 7)
- The decision-making criteria for committees (sections 13 to 16)
- Increasing the visible role of parents in the process (sections 11, 36, 41)
- Staging the introduction of different parts of the Bill, to support seamless transition in care for existing patients, the timely training of health professionals, and the development of general treatment plans (section 2)
- Setting maximum time frames for key actions by committees, to ensure responsiveness (sections 12, 21, 38, 39)
- Adjustment to one of the offences, and increasing the standard of proof to be met by the prosecution, to avoid that offence capturing people with genuine reasons to be unaware of the requirements of the Bill (section 28).

In addition to these consultations, the Government corresponded with leading researchers and practitioners in the field, both in Australia and internationally, seeking their input on specific aspects of the project in their areas of expertise. These were particularly important in helping to define the scope of the project, understanding what kinds of medical treatments the committee’s scrutiny should be aiming to limit or defer, and in designing new support services that will operate alongside the legislation. The government also engaged with the Australian Health Practitioner Regulation Agency at key stages in the project, seeking advice that there was no potential inconsistency between the reform and the Agency’s regulatory responsibilities.

## **CONSISTENCY WITH HUMAN RIGHTS**

### **Rights engaged**

The Bill engages the following rights under the *Human Rights Act 2004* (HR Act):

- Section 8 - Right to equality and non-discrimination (*promoted*)
- Section 9 – Right to life (*promoted*)
- Section 10 – Protection from torture and cruel, inhuman or degrading treatment etc (*promoted*)
- Section 11 – Right to protection of the family and child (*promoted and limited*)
- Section 12 - Right to privacy (*promoted and limited*)
- Section 21 – Rights to fair trial and fair hearing (*promoted*)
- Section 22 – Rights in criminal proceedings (*limited*)

## ***Rights Promoted***

### Section 8 - Right to equality and non-discrimination

Section 8 of the HR Act provides that everyone is entitled to enjoy their rights without discrimination of any kind and that everyone is equal before the law and entitled to the equal protection of the law without discrimination. This includes the need for special measures: different treatment for a group that is legitimate and necessary to promote equal enjoyment of rights by these groups.<sup>23</sup> The ACT government also has certain positive obligations to promote the right to equality and non-discrimination by having laws and measures in place to ensure full participation and diminish or eliminate conditions which could perpetuate discrimination. A 'special measure' will not be considered discriminatory under the HR Act, which means that differential treatment of people with variations in sex characteristics under this Act is not a limitation on the right to equality.

Ensuring non-discriminatory decisions are made about medical intervention for people with variations in sex characteristics requires special measures to deliver that equality. This is because “despite the best efforts of intersex human rights defenders, discrimination, stigmatisation and human rights violations, including harmful practices in medical settings, continue to occur in Australia and Aotearoa/New Zealand”.<sup>24</sup> The introduction of special measures has been recommended by multiple human rights assessments of Australian laws.

The Committee on the Elimination of Discrimination against Women in 2018 recommended Australia:

...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<sup>25</sup>

A United Nations Committee on the Rights of the Child report in 2019 stated Australia should be:

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<sup>23</sup> Australian Human Rights Commission, Rights to equality and non discrimination, <https://humanrights.gov.au/our-work/rights-and-freedoms/rights-equality-and-non-discrimination>

<sup>24</sup> Androgen Insensitivity Syndrome Support Group Australia, Intersex Trust Aotearoa New Zealand, Organisation Intersex International Australia and others, 2017, *Darlington Statement*, para. B, <https://darlington.org.au/statement/>

<sup>25</sup> United Nations Committee on the Elimination of Discrimination against Women, 2018, *Concluding observations on the eighth periodic report of Australia*, CEDAW/C/AUS/CO/8 [26].

explicitly prohibiting coerced sterilization or unnecessary medical or surgical treatment, guaranteeing the bodily integrity and autonomy of intersex children and providing adequate support and counselling to families of intersex children.<sup>26</sup>

A United Nations report on the Convention on the Rights of Persons with Disability in 2019 recommended that Australia:

Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary, invasive and irreversible medical interventions, including surgical, hormonal or other medical procedures on intersex children before they reach the legal age of consent.<sup>27</sup>

The Bill creates those special measures by establishing a board (section 29) comprised of people with expertise related to relevant aspects of care decision-making for intersex people (section 31), and giving committees of that board a responsibility to ensure prescribed persons are not subject to medical treatment decisions and reasons that a non-intersex person would not be subject to.

The Bill promotes this right both for children who have a variation in sex characteristics, and adults with a disability that means they are not making their own treatment decisions but are under guardianship orders for that purpose.

### Section 9 - Right to life

Everyone has the right to life including the right to not be arbitrarily deprived of life. Research has found that LGBTIQ+ people have increased risk of self-harming and suicidal thoughts and health outcomes for LGBTIQ+ Canberrans have been found to be significantly worse than their peers in Canberra.<sup>28</sup> Discrimination and prejudice towards intersex people are key factors in increasing the risk of mental illness and poor wellbeing outcomes.

In these circumstances, the UN HR Committee has noted that the right:

requires States parties to take special measures of protection towards persons in vulnerable situations whose lives have been placed at particular risk because of specific threats or pre-existing patterns of violence. Such persons include...intersex persons...<sup>29</sup>

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<sup>26</sup> United Nations Committee on the Rights of the Child, November 2019, *Concluding observations on the combined fifth and sixth periodic reports of Australia*, CRC/C/AUS/CO/5-6 [31b].

<sup>27</sup> United Nations Committee on the Convention on the Rights of Persons with Disability (CRPD), September 2019, *Concluding Observations: UN Report on Australia's Review of the CRPD*, CRPD/C/AUS/CO/2-3 [34b].

<sup>28</sup> ACT Health Directorate, 2021, LGBTIQ+ Health Scoping Study report.

<sup>29</sup> Human Rights Committee, International Covenant on Civil and Political Rights, *General Comment 36*, para. 23.

The Bill promotes the right to life by establishing a special measure to protect people with variations in sex characteristics. Sections 29 to 31 establish the Restricted Medical Treatment Assessment Board, with a membership that includes appropriate expertise in human rights and medicine, to provide scrutiny of proposed medical treatments of intersex people, who cannot give personal consent, assessing those treatments against the criteria in sections 13 to 16, which cover areas in which it is known that rights have not been upheld.

The right to life is also safeguarded by allowing urgent treatments, including those that may be necessary to save a person's life, to proceed without any delay that might result from oversight processes (section 10(2)).

#### Section 10 – Protection from torture and cruel, inhuman or degrading treatment etc

No-one may be subjected to medical or scientific experimentation or treatment without their free consent.

Section 13(1) promotes the right to not being subject to medical treatment without consent, by requiring the new statutory decision-maker to be satisfied, before approving a restricted medical treatment, that there is sufficient evidence that:

- (a) a person to whom a plan applies would suffer significant harm if the proposed treatment were not undertaken in accordance with the plan; and
- (b) the proposed treatment is no more restrictive of the ability to make a decision about a prescribed person's sex characteristics in the future than any alternative treatment option.

For cases where the medical treatment is urgent, the board does not have oversight of treatment decisions, and they proceed subject to the protections in existing law. However, the Bill includes a requirement on doctors to report to the board all urgent medical treatment that permanently affects a prescribed person's sex characteristics (section 43(2)(b)). This will ensure that the board is able to advise the Minister if it thinks the urgency provision may be being used in a manner inconsistent with protection of the rights of people with variations.

#### Section 11 - Right to protection of the family and children

The family is the natural and basic group unit of society and is entitled to be protected by society. Children, due to their particular vulnerabilities, have special rights under human rights law. This right to protection is in addition to all other rights, which children enjoy as individuals.

The rights in section 11 include governments supporting families when undertaking their responsibilities toward children:

The Committee urges States parties to take all necessary steps to ensure that parents are able to take primary responsibility for their children; to support parents in fulfilling their responsibilities, including by reducing harmful

deprivations, disruptions and distortions in children's care; and to take action where young children's wellbeing may be at risk.<sup>30</sup>

This includes that:

States parties are required to render appropriate assistance to parents, legal guardians and extended families in the performance of their child-rearing responsibilities, including ...ensuring that children receive necessary protection and care.<sup>31</sup>

The protection of the family is promoted in Part 3, which creates a system of treatment planning for people with variations in sex characteristics, who will in practice often be children, that promotes the delivery of advice to both the person with a variation and to their family. Section 16 requires committees to consider whether sufficient information has been provided, including whether a prescribed person has received appropriate support to participate in decision-making.

The Bill promotes special protection of the rights of children with variations in sex characteristics through ensuring:

- Oversight of the assessment of their capacity to make their own decision (section 16(a))
- That they are given, or have access to, appropriate support to assist them in understanding information (section 16(c))
- That they have received appropriate support to participate in decision-making about the treatment plan and to communicate their wishes freely; and that any wishes they communicate in relation to proposed treatment or their variation in sex characteristics are appropriately considered (section 16(e))

### Section 12 - Right to privacy

Section 12 of the HR Act protects individuals from unlawful or arbitrary interference with privacy, family, home or correspondence. The right encompasses the idea that individuals should have a separate area of autonomous development, interaction and liberty, free from excessive government intervention and unsolicited intrusion by other individuals. This includes protection of physical, psychological and bodily integrity.

The right to physical, psychological and bodily integrity is promoted for the reasons set out in respect of section 10 of the HR Act, above.

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<sup>30</sup> Committee On The Rights Of The Child, *General Comment 7*, para. 18.

<sup>31</sup> Committee On The Rights Of The Child, *General Comment 7*, para. 20.

## Section 21 – Rights to fair trial and fair hearing

The right to fair hearing is concerned with procedural fairness, and encompasses notions of equality in proceedings. It considers things such as accessibility, timeliness, appeal or review, and where needed, support to participate in proceedings.

This right is promoted through several features of the new approval process in the bill. These include:

- required time frames for committees to consider applications (section 12(1));
- consideration by committees of whether a prescribed person has received appropriate support to participate in decision-making (section 16(e));
- a requirement that committees share with applicants all evidence they have before them, and give applicants reasonable period of time in which to consider the information and make any changes to their application (section 20); and
- rights of both internal and external review (sections 35-42).

## ***Rights Limited***

### Section 11 - Right to protection of the family and child

#### 1. Nature of the right and the limitation (s28(a) and (c))

The right to protection of the family in the HR Act states “The family is the natural and basic group unit of society and is entitled to be protected by society”. This right has its origins in Article 23(1) of the *International Covenant on Civil and Political Rights*, which refers to people not being “subjected to arbitrary or unlawful interference with [their] privacy, family, home or correspondence...”<sup>32</sup> The definition of “arbitrary” in this context is broader than its ordinary meaning: the UN Human Rights Committee describes it extending to actions consistent with laws:

“arbitrary interference” can also extend to interference provided for under the law. The introduction of the concept of arbitrariness is intended to guarantee

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<sup>32</sup> ACT Government Justice and Community Safety Directorate, Human Rights Fact Sheet, *Right to protection of the family and children*; [https://www.justice.act.gov.au/\\_data/assets/pdf\\_file/0006/2072409/Fact-Sheet-D-s-11-Right-to-Protection-of-Family-and-Children-Human-Rights-Education.pdf](https://www.justice.act.gov.au/_data/assets/pdf_file/0006/2072409/Fact-Sheet-D-s-11-Right-to-Protection-of-Family-and-Children-Human-Rights-Education.pdf); United Nations International Covenant on Civil and Political Rights, Article 23(1).

that even interference provided for by law should be in accordance with the provisions, aims and objectives of the Covenant.<sup>33</sup>

Accordingly, this Bill may limit the right to the protection of the family from arbitrary interference, if the decision-making criteria followed by assessment committees are not in accordance with the provisions, aims and objectives of the Covenant.

Protecting the right of prescribed persons with variations in sex characteristics to be free of discrimination means preventing arguments regarding ‘medical necessity’ in treatment decision-making from being confused with other, non-essential, reasons to perform a treatment. This is particularly because of the evidence of courts and other decision-makers in this field uncritically assuming the best interests of a person involve conforming to norms of sex or gender. They have then concluded it is appropriate to undertake medical interventions that make bodies conform, removing the opportunity for the person to make choices about their own body.<sup>34</sup>

To prevent the abuse of these arguments, this Bill limits the reasons for which a treatment plan can be approved, by not permitting a plan to be made solely for the purpose of reducing discrimination or stigmatisation or a perceived risk of discrimination or stigmatisation.

## 2. Legitimate purpose (s28(b))

The stigma resulting from discrimination against people with variations in sex characteristics sometimes results in families or doctors seeking to implement permanent medical treatments not consistent with the principles. The AHRC report explained how this situation arises:

Stigma has resulted in part from prevailing social and cultural attitudes, which in part flow from ignorance and prejudice. This stigma has driven further harms, including motivating doctors to recommend medical interventions, and parents to consent to them. In turn, advice from some medical practitioners has reinforced and perpetuated stigma about variations in sex characteristics. Interventions have been experienced as reinforcing a cycle of stigma, where variations in sex characteristics are treated as a ‘problem’ that needs to be

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<sup>33</sup> United Nations Human Rights Committee, 1988, *General Comment 16*: Article 17 (The right to respect of privacy, family, home and correspondence, and protection of honour and reputation), para. 4.

<sup>34</sup> See, eg, O’Dwyer, S., 2017, ‘“Treatment” of Intersex Children as a Special Medical Procedure’, *Journal of Law and Medicine* 24, pp.870, 878; Richards, B., 2017, ‘Stretching the Boundaries of Parental Responsibility: Re Carla (Medical procedure) [2016]’, *Bioethical Inquiry* 14, pp.323–324; Kelly, F., and Smith, M.K., 2017, ‘Should Court Authorisation Be Required for Surgery on Intersex Children? A Critique of the Family Court Decision in Re Carla’, *Australian Journal of Family Law* 31 (2), pp.118–33; Richards, B.J., and Wisdom, T.L.C., 2019, ‘Re Carla: An Error in Judgment’, *QUT Law Review* 18 (2), pp.77–92; Jones, M., 2018, ‘Children’s Health Rights and Gender Issues’, *Children’s Rights in Health Care*, November, pp.382–424.

‘fixed’... The Commission notes that experiences of stigma may lead to unlawful discrimination under the Sex Discrimination Act.<sup>35</sup>

Treatments undertaken for these reasons have caused serious harm to people with variations in sex characteristics. These experiences include loss of sensitivity or inability to experience orgasm, complications of treatments requiring additional surgeries, experiencing anxiety or depression, or having imposed on them medical treatments to conform with a gender that was not in accord with their own identity, in all cases involving treatments to which they did not give personal consent.<sup>36</sup> These treatments are not medically necessary.

As noted earlier, the ACT HR Act and *Discrimination Act 1991* make it unlawful to discriminate on the basis of a person’s sex characteristics. This Bill implements additional protection in an area of known human rights risk.

### 3. Rational connection between the limitation and the purpose (s28(d))

There is a rational connection between the limitation on the right to protection of the family and the objective, as the creation of guidance to the decision-maker that prevents inappropriate rationales for treatment necessarily means those decisions are not being solely made between a family and health professionals. Without the requirement of section 14(a), there is no means to identify and prevent treatment options that violate children’s rights.

### 4. Proportionality (s28 (e))

The Bill carefully balances competing rights of the prescribed person and their family. In order to protect a prescribed person’s right to freedom from discrimination of any kind, and specifically from discrimination on the basis of their sex characteristics, it is necessary to provide a mechanism that ensures that private decision-making between families and doctors does not unnecessarily infringe the protected person’s rights.

Where treatment is proposed solely for such reasons, the appropriate pathway is not to undertake medical treatment that will make irreversible changes to a prescribed person’s body, but to address assumptions regarding stereotypes and the sources of discrimination or stigmatisation through less invasive means. These could include

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<sup>35</sup> Australian Human Rights Commission, 2021, *Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics*, pp.60-61.

<sup>36</sup> Australian Human Rights Commission, 2021, *Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics*, pp. 51-60; Crouch N.S., Liao, L.M., Woodhouse, C.R., et al., 2008, ‘Sexual function and genital sensitivity following feminizing genitoplasty for congenital adrenal hyperplasia’, *Journal of Urology* 179, pp.634–8; Jones, M., 2017, ‘Intersex genital mutilation a western version of FGM’, *International Journal of Children’s Rights*, 25(2), pp.396-411; Jones T. et al., 2016, *Intersex: Stories and Statistics from Australia*, Open Book Publishers, Chapter 5; Hart, B. and Jane Shakespeare-Finch, J., 2022, ‘Intersex lived experience: trauma and posttraumatic growth in narratives’, *Psychology & Sexuality* 13, pp.912-930.



providing psychosocial supports or creating safe and inclusive environments through training and awareness. Discrimination, stigmatisation and pressure to conform with sex or gender stereotypes are community issues that the community as a whole must take responsibility for, rather than allowing measures to continue that involve the individual experiencing harm through having their body ‘corrected’. The source of the harm is the existence of, and lack of protection from, discrimination. The person’s body is not the source of the harm.

Over the three years of the project leading to introduction of this Bill, steps were taken to determine whether there is ever any medical evidence to justify treatments being performed for the sole reason of reducing stigmatisation or discrimination. This included review of the research literature regarding medical treatment of people with variations in sex characteristics, and of the reports and findings of other independent bodies that have examined similar issues.

As set out in more detail below, this examination found no published evidence that demonstrates benefits from permanent medical treatments being conducted without a person’s own consent for reasons relating to management of discrimination, stigmatisation or their effects.

In these circumstances, such treatments should only occur when the person themselves has the capacity to make decisions about the treatment, and board committees will be supported in making this determination through a criterion in the sections of the Bill that govern the process of assessing proposed restricted medical treatments (Section 16(a)).

If the person is a child, the child may choose to go ahead with the treatment once they have decision-making capacity, understanding and awareness of consequences to make the decision for themselves. This may be earlier than 18 years old where the child is legally competent to make their own decision.<sup>37</sup> The Bill is framed to allow any person with such legal capacity, including a child, to make the decision for themselves (through the definition of who is a protected person in section 9), but protects people, particularly children, from having others make such decisions for them.

#### *Why permanent medical treatment is medically unnecessary when addressing discrimination or stigmatisation*

Early intervention, particularly surgery, to address stigmatisation or discrimination affecting a child with a variation in sex characteristics cannot ever be reliably determined to be in the best interests of the child:

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<sup>37</sup> *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112; *Secretary, Department of Health and Community Services v JWB and SMB* (Marion’s case) [1992] 175 CLR 218.

A key issue here is that determining the best interests for the intersex child cannot be established with enough certainty to avoid the risk of harm that surgical intervention may pose later in life. Parental welfare does in part consider the child and the potential for distress within the family and child's upbringing that being intersex may cause, but there is little research to support this. Whereas, more research to the contrary is published and identifies the detriment that is caused to both sex or gender identity and physical well-being following the complications of surgery. Beyond physical harm is the psychological harm caused as a result of not only physical appearance and discomfort but also the fact that the assigned sex can be 'incorrect' in identifying with a sex and subsequent gender identity later in life. This uncertainty and therefore potentially catastrophic error as a result of infant genital-normalizing surgery is, I argue, the fundamental flaw in the promotion of early surgery.<sup>38</sup>

There is no evidence that permanent medical treatment can reduce psychological harm, bullying, stigma or discrimination. Yet these treatments come with the medical risks of the treatment itself as well as the risk of undertaking medical treatment that the person themselves would not choose.<sup>39</sup>

Some stakeholders suggested there are situations where it is appropriate and potentially in the best interests of the child to undertake permanent medical treatment for the purpose of addressing discrimination or stigmatisation or psychological harm arising from discrimination or stigmatisation. During the Bill's development, some stakeholders argued that if the treatment is not permitted in such circumstances, then decisions made under this Bill might permit further psychological harm to the child or person.<sup>40</sup>

Based on published evidence and studies available, this position is not supported. It reflects hypothetical risks or fears not supported by an evidence base, perpetuated by cultural conditioning of gender norms, and gives them more weight than the risks that medical treatment itself can present:

Some surgeons have made reference to social rather than medical concerns (or emergencies) such as “the locker room test”—referring to the idea that children may be bullied at school if their genitalia are revealed to

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<sup>38</sup> Horowitz, E., 2017, 'Intersex children: Who are we really treating?' *Medical Law International* 17(3), pp. 183-218.

<sup>39</sup> Horowitz, E., 'Intersex children: Who are we really treating?' *Medical Law International* 17(3), pp. 183-218; Garland, F. and Travis, M., 2020, 'Temporal Bodies: Emergencies, Emergence, and Intersex Embodiment', in Dietz, C., Travis, M., and Thomson M. (eds), *A Jurisprudence of the Body*, Springer, pp.127-128.

<sup>40</sup> This suggestion is also discussed – though not in an Australian context – in Behrens, K. G., 2020, A principled ethical approach to intersex paediatric surgeries. *BMC Medical Ethics* 21, pp.1-9.

their peer group (Griffiths 2020; Fausto-Sterling 2000; Meoded Danon 2018).

In the largest study of medical professionals working with intersex children, Liao et al. found that none of the participants had come across instances of children being bullied for their genital appearance (2019: 3). Nonetheless, “unmanageable negative psycho-social consequences were generally assumed” (Liao et al. 2019: 3). Such justifications ignore the very real and immediate harms wrought through surgery on the child in the present in favour of focusing on imagined harms that locate the intersex person in a state of perpetual adolescence (in the locker room, at the urinal, dating, having sex).<sup>41</sup>

There is also a lack of evidence to show it is possible to successfully treat the impacts of stigmatisation or discrimination through permanent medical treatments:

cosmetic anomalies left uncorrected have little impact on psychological well-being. This point is consistent with quantitative psychological research involving non-clinical populations that has shown how children’s subjective distress is not predicted by their rating of themselves as atypical. Rather, it was children who felt under pressure to conform who reported higher levels of distress (Yunger, Carver, & Perry, 2004). This non-clinical psychological research suggests that children raised with visible atypicality may not necessarily be distressed by that atypicality, but may actually be distressed by interventions (i.e., manifestations of social pressure) to make them appear more typical.<sup>42</sup>

Despite the lack of evidence to support early medical treatment, this widespread practice has meant that it can be difficult to even locate people with variations who are untreated or treated later in life, to assess whether early intervention is justified. In the only study of people with a variation in sex characteristics that had enough subjects both with and without medical intervention to form statistically valid conclusions, lack of medical treatment was not associated with poorer psychological well-being.<sup>43</sup>

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<sup>41</sup> Garland, F. and Travis, M., 2020, ‘Temporal Bodies: Emergencies, Emergence, and Intersex Embodiment’, in Dietz, C., Travis, M., and Thomson M. (eds), *A Jurisprudence of the Body*, Springer, pp.127-128; Fausto-Sterling, A., 2000, *Sexing the Body: Gender Politics and the Construction of Sexuality*, New York: Basic Books; Griffiths, D., 2020, ‘Queering the Moment of Hypospadias “Repair”’, *GLQ* 27 (4), pp.499–523; Meoded Danon, L., 2018, ‘Time matters for intersex bodies: Between socio-medical time and somatic time’, *Social Science and Medicine* 208, pp.89–97; Liao, L.-M., Hegarty, P., Creighton, S., et al., 2019, ‘Clitoral Surgery on Minors: An Interview Study with Clinical Experts of Differences of Sex Development’, *BMJ Open* 9, e025821.

<sup>42</sup> Roen, K. and Pasterski, V., 2014, ‘Psychological research and intersex/DSD: recent developments and future directions’, *Psychology & Sexuality* 5(1), pp. 102-116; Yunger, J. L., Carver, P. R., & Perry, D. G., 2004, ‘Does gender identity influence children’s psychological well-being?’ *Developmental Psychology*, 40, pp.572–582.

<sup>43</sup> Dodds et al., 2008 cited in Roen, K. and Pasterski, V., 2014, ‘Psychological research and intersex/DSD: recent developments and future directions’, *Psychology & Sexuality* 5(1), pp. 102-116.

One of the main reference documents in the medical literature, referred to as the 2006 Consensus Statement, stated that there is no systematic evidence for the “belief” that surgery “performed for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents”.<sup>44</sup> Ten years later, a major update of that statement was even more definite:

There is no evidence regarding the impact of surgically treated or non-treated DSDs [disorders of sex development] during childhood for the individual, the parents, society or the risk of stigmatization.<sup>45</sup>

The Australian Human Rights Commission considered this matter and concluded “interventions based on notions of normalising sex characteristics and other psychosocial rationales do not meet the standard of medical necessity” and these treatments should not be authorised by an oversight body.<sup>46</sup> It did not recommend discretion around this.

The application of this criterion in Section 14 (b) in the Bill supports a movement away from discrimination that negatively affects wellbeing, particularly of children:

‘Normalisation’ surgery is, from a psychological point of view, shame management (Liao et al., 2015). Unfortunately, the experience of childhood genital surgery stigmatises bodily diversity as being shameful rather than facilitating the intended management of any perceived shame associated with physical difference (Engberg et al., 2016; Liao et al., 2019). Schweizer et al. (2017) reported a significant correlation between number of surgical interventions and level of body dissatisfaction... The findings of this analysis [are that] experiencing childhood genital surgery stigmatises bodily diversity, rather than facilitates the management of any perceived shame resulting from physical difference.<sup>47</sup>

The application of this criterion by the assessment committee means that discrimination or stigmatisation experienced by people with variations in sex

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<sup>44</sup> Hughes, I.A., Houk, C., Ahmed, S.F., Lee, P.E., and LWPES/ESPE Consensus Group, 2006, ‘Consensus Statement on Management of Intersex Disorders’, *Archives of Disease in Childhood* 91, pp.554–63.

<sup>45</sup> Lee, P.A., Nordenström, A., Houk, C.P., et al., 2016, ‘Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care’, *Hormone Research in Paediatrics* 85 (3), p.176.

<sup>46</sup> Australian Human Rights Commission, 2021, *Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics*, pp. 126, 188.

<sup>47</sup> Hart, B. and Jane Shakespeare-Finch, J., 2022, ‘Intersex lived experience: trauma and posttraumatic growth in narratives’, *Psychology & Sexuality* 13, pp. 9, 14; Liao, L., Wood, D., & Creighton, S. M., 2015, ‘Parental choice on normalising cosmetic genital surgery: Between a rock and a hard place’, *British Medical Journal* 351, p.h5124; Liao, L., Hegarty, P., Creighton, S., Lundberg, T., & Roen, K., 2019, ‘Clitoral surgery on minors: An interview study with clinical experts of differences of sex development’, *BMJ Open*, 9(6), p.e025821; Engberg, H., Möller, A., Hagenfeldt, K., Nordenskjöld, A., & Frisén, L., 2016, ‘The experience of women living with congenital adrenal hyperplasia: Impact of the condition and the care given’, *Clinical Endocrinology* 85(1), pp.21–28; Schweizer, K., Brunner, F., Gedrose, B., Handford, C., & Richter-Appelt, H., 2017, ‘Coping with diverse sex development: Treatment experiences and psychosocial support during childhood and adolescence and adult well-being’, *Journal of Pediatric Psychology*, 42(5), pp.504–519.

characteristics will be managed in the same way as other forms of discrimination, such as based on race or sex. It is not considered appropriate to address discrimination or stigmatisation of a child of colour by requiring them to change or disguise their racial identity. It is not considered appropriate to address sexist treatment of a child by altering their appearance or behaviour to conform to a gender norm. It is not considered appropriate to recommend that women alter their dress or activities to avoid harassment. This bill protects children from irreversible modifications of their bodies performed for similarly inappropriate reasons.

The Bill supports building capacity of children and others who might lack decision-making capacity, through provisions regarding the supply of sufficient information to protected persons and through supporting decision-making by anyone, including a child, with capacity (section 16(a) and (c)). With supports, education, and by giving them appropriate opportunities to understand and make choices about their own treatment, they may be able to have, and exercise, legal capacity in their own right. The Bill gives children protection while supporting them to exercise capacity where it is possible and appropriate.

Two alternatives to the approach in the Bill were considered:

- Using non-legislated guidelines to support healthcare decisions, which would remain private between health care practitioners and families.
- Allowing discretion on the part of the assessment committee to potentially approve treatments where the sole reason for the treatment was to address discrimination or stigmatisation.

The first approach was rejected on the grounds that there are existing guidelines that explicitly state the limitation of treatment for stigmatisation, and these have not resolved the issue.<sup>48</sup> Published studies also show health practice guidelines can have poor levels of compliance, which is not appropriate in an area where there are serious human rights risks if guidelines are not followed.<sup>49</sup>

The second approach was rejected as it places children at risk of treatments that lack evidence of any effectiveness, as set out in detail above. Critical analysis of

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<sup>48</sup> Lee, P.A., Nordenström, A., Houk, C.P., et al., 2016, 'Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care', *Hormone Research in Paediatrics* 85 (3), p.176.

<sup>49</sup> Braithwaite, J., Hibbert, P.D., Jaffe, A., et al., 2018, 'Quality of Health Care for Children in Australia, 2012-2013', *JAMA* 319 (11), pp.1113–24; Cabana, M.D., Rand, C.S., Powe, N.R., et al., 1999, 'Why Don't Physicians Follow Clinical Practice Guidelines?: A Framework for Improvement', *JAMA* 282 (15), pp.1458–65; Millington, S., Arstall, M., Dekker, G., et al., 2020, 'Adherence to Clinical Practice Guidelines for South Australian Pregnant Women with Cardiac Conditions between 2003 and 2013', *PLOS ONE* 15 (3), p.e0230459; Zillén, K., Garland, J., and Slokenberga, S., 2017, *The Rights of Children in Biomedicine: Challenges Posed by Scientific Advances and Uncertainties*, Committee on Bioethics of the Council of Europe.

both medical reasoning<sup>50</sup> and court reasoning<sup>51</sup> in this field indicate that these inappropriate arguments will continue to be advocated and sometimes erroneously accepted by decision-makers. A recent Australian paper endorsed doctors considering undertaking treatments they would not normally recommend, for reasons related to possibility of stigmatisation or discrimination, such as the “possibility that a child will not be accepted by parents in the sex of rearing that would usually be recommended by doctors” or “risk of social isolation, restrictions or difficulties, for example, caused by embarrassment or social stigma”.<sup>52</sup> There is a risk decision-makers will succumb to such arguments if not sufficiently guided. The appropriate way to ensure that less invasive treatments and psychosocial supports are the supported treatment pathways, is the requirement set out in section 16(a) of the Bill.

The limitation on the right is targeted. As set out earlier, the constraint on reasons to be considered in approving restricted medical treatment is confined to the one area of particular risk. All other areas of reason can be considered by assessment committees. The setting aside of evidence regarding treatment for discrimination or stigmatisation does not preclude evidence of psychological harm more generally or the prescribed person's mental health from being considered. Any evidence about the protected person's mental health as it relates to other aspects of their life or their body is relevant and can be considered.

The limitation on this right is also balanced by the many other ways that parental responsibilities and duties are upheld by the Bill. These include through parents being able to:

- be applicants for treatment plans (section 11(2)(b)(i))
- meet and give evidence to the assessment committees (section 18(1))
- obtain a review of any decision they are not satisfied with, by both a new committee of the Board and by ACAT (sections 36, 37, 41).

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<sup>50</sup> Carpenter, M., 2018, ‘The “Normalisation” of Intersex Bodies and “Othering” of Intersex Identities’. In, Scherpe, J., Dutta, A., and Helms T., (eds), *The Legal Status of Intersex Persons*, Cambridge, England: Intersentia, pp.445–514.

<sup>51</sup> O’Dwyer, S., 2017, “Treatment” of Intersex Children as a Special Medical Procedure’, *Journal of Law and Medicine* 24, pp.870, 878; Kelly, F., and Smith, M.K., 2017, ‘Should Court Authorisation Be Required for Surgery on Intersex Children? A Critique of the Family Court Decision in Re Carla’, *Australian Journal of Family Law* 31 (2), pp.118–33; Richards, B.J., and Wisdom, T.L.C., 2019, ‘Re Carla: An Error in Judgment’. *QUT Law Review* 18 (2), pp.77–92; Jones, M., 2018, ‘Children’s Health Rights and Gender Issues’. *Children’s Rights in Health Care*, November, pp.382–424.

<sup>52</sup> Gillam, L., 2020, ‘Ethical Principles for the Management of DSD’. In Hutson, J.M., Grover, S.R., O’Connell, M.A., et al., (eds), *Disorders/Differences of Sex Development: An Integrated Approach to Management*, Singapore: Springer, pp.182-3. Other clinical guidance that supports early surgery for reasons other than medical necessity include Speiser, P.W., Arlt, W., Auchus, R.J., et al., 2018, *Congenital Adrenal Hyperplasia Due to Steroid 21-Hydroxylase Deficiency: An Endocrine Society\* Clinical Practice Guideline*.

Parents also remain the ones who ultimately decide whether to consent to a treatment, where their child is not providing legal consent themselves.

### Section 12 - Right to privacy

#### 1. Nature of the right and the limitation (s28(a) and (c))

The right to privacy includes the protection of individuals living their private life without excessive government interference. This right is limited to the extent that the Bill creates new oversight by government of restricted medical treatments made in relation to prescribed persons. These decisions will no longer be solely private matters between the prescribed person, or decision-maker for the prescribed person, and their doctors. Where a treatment is proposed that will have permanent effects on the sex characteristics of a prescribed person, it will require approval by a committee of the Restricted Medical Treatment Assessment Board.

This right is also limited by the requirement that reportable treatments are reported by doctors to the president of the Board (section 43). Reportable treatments comprise:

- (a) restricted medical treatment under a treatment plan;
- (b) urgent restricted medical treatment;
- (c) treatment that would have been a restricted medical treatment, had it not been to treat a condition that is excluded from the scope of the Bill's oversight requirements by virtue of a regulation made under section 7(1)(c).

This right is also limited by a provision that allows a decision-maker to give consent to disclose personal information about themselves or a prescribed person for whom they are a decision-maker (section 18(3)).

#### 2. Legitimate purpose (s28(b))

The legitimate purpose of creating a new oversight mechanism is to ensure that treatment decisions for people with variations in sex characteristics uphold the rights of the prescribed person receiving the treatment. In particular, their rights not to be subjected to medical treatment without their free consent; to enjoy their human rights without discrimination; and the rights of a child to special protection, particularly to ensure they are being consulted and heard in the decision-making process.

This protection is necessary because of the documented harms, including human rights violations, that can occur for people with variations in sex characteristics. Research in Australia and internationally indicates that the circumstances around contemporary medical care for intersex people present ongoing challenges including the risk of violation of the human rights of intersex children:

- Prevailing cultural expectations and medical practice include assignment of sex and gender at the earliest opportunity;<sup>53</sup>
- Stress, anxiety, cultural norms, and a lack of definitive medical guidelines all influence parental decision-making, often in favour of early medical intervention;<sup>54</sup>
- Gender ‘normalising’ surgeries are conducted on young children;<sup>55</sup>
- There is no consensus in the medical literature around optimal approaches to surgical intervention on people with intersex variations;<sup>56</sup>
- Poor evidence for the long-term outcomes of many early medical interventions means that for some intersex people, the literature supports later medical intervention, including when the patient can make their own decisions;<sup>57</sup> and
- In the largest survey of intersex people conducted in Australia, published in 2016, the results showed that “One fifth of the participants had been given no information at all about any surgical or hormonal treatments they had received and the majority were not told about risks related to the interventions, their right to not have these often life-changing treatments or other related information. Participants reported various physical, mental and psychological impacts from treatments.”<sup>58</sup>

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<sup>53</sup> See for example Lee, P.A. et al., 2016. ‘Global disorders of sex development update since 2006: perceptions, approach and care’, *Hormone Research in Paediatrics*, vol. 85, pp.168-170, 173-176; Cresti, M. et al., 2018, ‘Intersexual births: the epistemology of sex and ethics of sex assignment’, *Bioethical Inquiry* 15, pp.557-568; Kearsley, I. and Hutson, J.M., 2017, ‘Disorders of sex development (DSD): not only babies with ambiguous genitalia. A practical guide for surgeons’, *Pediatr Surg Int.* 33, pp.355-361.

<sup>54</sup> See for example Rolston, A.M. et al., 2015, ‘Parental reports of stigma associated with child’s disorder of sex development’, *Int J Endocrinol*, article ID 980121; Wolfe-Christensen, C. et al., 2017, ‘Changes in levels of parental distress after their child with atypical genitalia undergoes genitoplasty’, *Journal of Pediatric Urology* 13, pp.32.e1-32.e6; Markosyan, R. and Faisal Ahmed, S., 2017, ‘Sex Assignment in Conditions Affecting Sex Development’, *J Clin Res Pediatr Endocrinol.* 9(Suppl 2), pp.106–112; Timmermans, S. et al., 2019, ‘Gender destinies: assigning gender in disorders of sex development-intersex clinics’, *Sociology of Health & Illness* 41(8), pp.1520-1534; Davis, G., 2015, *Contesting intersex*, New York University Press, chapter 5.

<sup>55</sup> See for example Rolston et al., 2015, above; Wolfe-Christensen et al., 2017, above; Yankovic, F. et al., 2013, ‘Current practice in feminizing surgery for congenital adrenal hyperplasia; a specialist survey’, *Journal of Pediatric Urology* 9, pp.1103-1107; Wisniewski, A.B. et al., 2019, ‘Management of 46,XY differences / disorders of sex development (DSD) throughout life’, *Endocrine Reviews* 40(6), p.1561; Australasian Paediatric Endocrine Group, 27 June, 2013, *Submission of the Australasian Paediatric Endocrine Group to the Senate Inquiry Into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development*.

<sup>56</sup> See for example Vora, K. and Srinivasan, S., 2020, ‘A guide to differences/disorders of sex development/intersex in children and adolescents’, *Australian Journal of General Practice* 49(7).

<sup>57</sup> See for example Mouriquand, P.D.E. et al., 2016, ‘Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how?’, *Journal of Pediatric Urology* 20, pp.1-11; Carmack, A. et al., 2016, ‘Should Surgery for Hypospadias Be Performed Before An Age of Consent?’, *The Journal of Sex Research* 53(8), pp.1-12.

<sup>58</sup> Jones, T. et al., 2016, *Intersex: Stories and Statistics from Australia*. Cambridge, UK: Open Book Publishers, p.3.



The legitimate purpose of the reporting requirements is so that the Board and the government have information to determine whether restricted medical treatments are occurring under the treatment plans that have been approved, and whether other treatments are occurring on prescribed persons who have variations in sex characteristics (including variations that have been excluded from the scope of oversight decisions).

Two sections in the Bill ('the privacy provisions') – section 18(3) and section 22(3)(a) – create special procedures to prevent the publication of information that may breach a prescribed person's right to privacy, except in certain circumstances.

Section 18 prevents an assessment committee from disclosing to another party a prescribed person's identity without the written consent of a decision-maker for the prescribed person. The legitimate purpose of this provision is to ensure that, if an assessment committee wishes to seek advice on an individual treatment plan from someone who may not know the prescribed person, they do not disclose the person's identity without first checking that a decision-maker for that prescribed person agrees that the disclosure is necessary. The reason that this is not made dependent on the agreement of the prescribed person themselves is that many prescribed persons will be unable to express a view at all (being infants or newborns), and others may not support the sharing of identifying information, but a decision-maker may need to conclude that it is in their best interests that the information be shared so that medical advice can be obtained. The ability to share personal information under section 18 will be particularly needed when it is impossible to avoid the prescribed person's identity being able to be worked out by a doctor in the same hospital system as the treating team, when they are given enough detail about the case to enable them to provide informed advice. Section 18 is designed to ensure that a pathway exists for sharing essential information, in a situation where the possibility of a prescribed person's identity being worked out could otherwise result in no information being shared at all.

In section 22, the legitimate purpose of preventing the disclosure of a prescribed person's identity in a submission to a public consultation on a general treatment plan, unless they have expressed a wish to have it published, is to ensure there is a mechanism by which a prescribed person who *wants* their identity to be known, can have their wishes implemented.

### 3. Rational connection between the limitation and the purpose (s28(d))

There is a rational connection between the limitation on the right to privacy and the objective as the creation of the new board allows the introduction of safeguards and oversight of the rights, that otherwise would not be present. The board applies multi-disciplinary expertise currently not always present in these sensitive decision-making processes, guarantees procedural fairness, and tests that there has been sufficient participation of the prescribed person in decision-making consistent with rights in the

*Convention on the Rights of the Child and the Convention on the Rights of Persons With Disabilities.*

The rational connection between the limitation on the right to privacy and the reporting requirements is that, without the requirements, the board would have no legal capacity to have information about treatments being undertaken. It would therefore be unable to determine the effects of its decisions, and the board and government would be unable to assess whether the Bill is effective in meeting its goals for regulating certain treatments for prescribed people with variations in sex characteristics.

In the case of section 18(3), the rational connection between the limitation on the right to privacy and the provision is that without it, the board would lack the ability to reveal private information about people who were subject to its proceedings where revealing their identity would be necessary in order to obtain sufficient information to allow them to fulfil their statutory function.

In the case of section 22(3), the rational connection is that if this provision was not included, the prescribed person would not have control over their identifying information in a general treatment plan consultation process. If the assessment committee publishes identifying information, it would violate their right to privacy. If instead the committee withheld the submission, this would mean the prescribed person would lose the capacity for their submission to be considered by participants in the general treatment plan process. Section 22(3)(a) ensures their privacy and autonomy are protected and prescribed persons can have a say in the development of general treatment plans that might affect them.

#### 4. Proportionality (s28(e))

The approach in the Bill to the oversight mechanism is the least restrictive available option that achieves the objective. Alternative options that were considered were:

- A. A professional disciplinary rule, to define certain treatments as constituting professional misconduct or unprofessional conduct by a health professional under the Health Practitioner Regulation National Law, as it is incorporated in the ACT; or
- B. a non-legislative standard applicable to ACT Government health institutions prohibiting deferrable medical interventions on intersex people without personal consent.

Option A would not achieve the objective because the Australian system of professional disciplinary oversight is through peer-based regulation within health professions. Because some published medical literature and existing practice accepts the types of medical interventions on intersex people that this reform seeks to defer, peer-based review would not find it to be outside the range of possible options, and therefore could not result in corrective or disciplinary action. Practitioner regulation is not designed to drive significant changes in practice. For this approach

to work, the peer assessment system itself that is the foundation of the professional regulatory framework would have to be altered, which is outside the scope for this reform.

Option B would not achieve the objective for several reasons. It would not provide adequate protection, because it would cover public health settings, but not private practice. As a result, this option would also not achieve effective non-discriminatory protection, because the way rights were upheld would depend on whether the health service was public or private. Published studies also indicate problems with compliance with non-legislated approaches to changing health care practice.<sup>59</sup>

The limitation of the right is narrowly targeted in several ways. These are by applying it only when:

- The medical procedure is not urgent (see sections 25, 26 and Dictionary);
- The treatment affects the person's sex characteristics (section 8);
- The treatment will permanently change the person's sex characteristics (section 8); and
- The person does not have capacity to consent to the medical procedure for themselves (sections 9, 14(a)).

Intrusion into the privacy of the individual and their family is also kept as narrow as possible by ensuring that parents or guardians retain a central role in decision-making. This includes through being able to be applicants for treatment plans (section 11(2)), and applicants for reviews of decisions (sections 36 and 41). The Bill does not change the fact that decision-makers for prescribed persons, such as parents, still need to consent to actual treatments, as is already the case.

The reporting requirements are the only available option to achieve the objective. Without the reporting requirements, the assessment board and the government will not know what the effects of the new oversight regime are, and therefore whether the rights it is intended to promote are being promoted. Specifically, the board would be unable to meet its responsibility under section 30(b) of the Bill, to advise the Minister about and make recommendations on which variations in sex characteristics should be covered by this Act. To provide this advice, the board needs to know whether treatments are being performed on people with variations in sex characteristics, including the variations that have been excluded by regulation from the approval provisions. Without this provision, the board and the Minister would also not be able

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<sup>59</sup> Braithwaite, J., Hibbert, P.D., Jaffe, A., et al., 2018. 'Quality of Health Care for Children in Australia, 2012-2013', *JAMA* 319 (11), pp.1113–24; Cabana, M.D., Rand, C.S., Powe, N.R., et al., 1999, 'Why Don't Physicians Follow Clinical Practice Guidelines?: A Framework for Improvement', *JAMA* 282 (15), pp.1458–65; Millington, S., Arstall, M., Dekker, G., et al., 2020, 'Adherence to Clinical Practice Guidelines for South Australian Pregnant Women with Cardiac Conditions between 2003 and 2013', *PLOS ONE* 15 (3), p.e0230459.

to know how frequently the urgent medical treatment exception (section 10(2)), which allows treatments to occur without an approved treatment plan, was being invoked.

The reporting requirements are limited to restricted medical treatments (or that would be restricted, had the variation in sex characteristics not been excluded from oversight by the regulation), and are invoked only for prescribed persons. Personal information held by the assessment board is protected by the Privacy Principles in the *Health Records (Privacy and Access) Act 1997*, and the assessment board's annual report is expressly prohibited from including information that identifies a prescribed person or a decision-maker for a prescribed person (Section 44(2)).

The privacy provisions relating to publishing a prescribed person's identifying information are the least restrictive available option that achieves the objective. An alternative to having these provisions would be to prevent the board from publishing identifying information at all. This would have undesirable effects. First, it would prevent the board from disclosing the identity of a prescribed person even if that person wanted their identity known. In the case of individual treatment plan consultation (section 18(3)), this could have the effect of preventing the board from initiating consultation mechanisms like roundtables or joint meetings at which the prescribed person and/or their decision-makers and expert advisers outside the treating team were present together. In the case of general treatment plan submissions (section 22(3)), this would have the effect of preventing the publication of a submission from a prescribed person, when the person themselves wanted their submission published. Where the prescribed person is a child, this would impinge on the right of the child to freedom of expression.<sup>60</sup>

Section 22 supports the right to privacy in the context of a public consultation process about general treatment plans. This is a process where an assessment committee is calling for submissions, and will be telling people it plans to publish them (as required by section 22(2)). Anyone making a submission under this section will therefore understand the expectation that their submission is to be published. It is in this context that some additional protection is being provided to prescribed persons. For other submitters, it will be assumed that they are agreeing to publication by participating in a process they have been told is public. For prescribed persons, however, section 22(3)(a) will require the committee to consider whether their submission identifies them or allows their identity to be worked out. If it does, the committee will need to be satisfied that it is consistent with the prescribed person's will and preferences that that information is published. For example, this may be satisfied if the prescribed person in their submission, or in a covering letter, refers to the process being public and that they want to participate in that. If there is no clear indication of their intention in the submission, the assessment committee

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<sup>60</sup> United Nations *Convention on the Rights of the Child*, Article 12.

would need to seek confirmation from the prescribed person that they wanted their identity to be published as part of the submission.

In addition, section 22(3)(a)(ii) will mean that, as well as checking with the prescribed person, the committee also will not publish information from a decision-maker, if that would allow the identity of a prescribed person to be worked out, unless the committee has evidence that publication is consistent with the will and preferences of that prescribed person. If a submission from a guardian, for example, named the prescribed person they care for in discussing appropriate care for that person's variation in sex characteristics, the committee would not publish that identifying information unless it was satisfied that this was consistent with the will and preferences of that adult under guardianship order.

The committee has an additional mechanism to provide protection of privacy. Section 22(3)(c) gives it the authority to not publish information, even if consistent with a protected person's will and preferences, if it has information that leads it to consider that publication could cause harm to that individual. This could include a request from a prescribed person's parent or guardian giving reasons why they think a submission from their child or adult under their care should not be published.

The privacy provisions are limited to specific situations where there may be a benefit to the prescribed person and their family from having information made available by the board to others. In contrast, the board is expressly prevented from disclosing such information in other contexts, including in its annual report (see above), and when initiating consultation on a general treatment plan (section 21(5)).

### Section 13 – Right to freedom of movement

#### 1. Nature of the right and the limitation (s28(a) and (c))

The right to freedom of movement in section 13 of the HR Act includes the right to enter and leave the ACT.

The right to freedom of movement may be subject to reasonable limits. The nature of the right is relevant when considering what is reasonable.

This Bill limits the right to freedom of movement by criminalising the conduct of travelling outside of the ACT for the purpose of having restricted medical treatment performed on a prescribed person without approval from an assessment committee. The limit does not apply if an assessment committee has approved the treatment.

The limit will apply to a person responsible for arranging medical treatment for another person (commonly a parent for a child).

#### 2. Legitimate purpose (s28(b))

The limit on travelling outside the ACT for restricted medical treatment that is not approved is intended to prevent people from deliberately circumventing the scheme. This preserves the integrity of the scheme and applies the scheme's oversight to ACT residents. Without this limit, it is possible that most treatment would take place outside the ACT without the oversight of the scheme, removing the ability for the scheme to improve care for the people undergoing this treatment.

### 3. Rational connection between the limitation and the purpose (s28(d))

There is a rational connection between the limit on seeking restricted medical treatment outside the ACT without approval under a treatment plan and the purpose of the scheme, to ensure that treatment decisions for people with variations in sex characteristics uphold the rights of the prescribed person receiving the treatment.

The adverse effects of restricted medical interventions, performed for inappropriate reasons or without adequate care, on people with variations in sex characteristics, can be extremely serious. Some of the outcomes that have been evidenced include lifelong psychological or physical pain, and unnecessary and permanent loss of fertility. It is appropriate there be criminal consequences for deliberate and reckless disregard for laws designed to protect vulnerable people.

### 4. Proportionality (s28 (e))

The approach in the Bill to travelling outside the ACT for the purposes of restricted medical treatment is the least restrictive available option that achieves the objective of preserving the integrity of the scheme and applying the scheme's oversight to ACT residents.

The person responsible for arranging the travel may apply to the board for approval of a treatment plan. If approval is given, the limitation on travel no longer applies.

As discussed above, the section 27 offence of arranging or authorising a restricted medical treatment requires a mental element of knowledge of the regulatory scheme. This is intended to ensure that a person can only be convicted of the offence if they can be shown to have been aware of the scheme that they were circumventing.

The penalties have been drafted with reference to other offences across ACT and national laws, as explained under 'offences' in the section on the main features of the Bill, above.

The conduct captured by the offence is targeted to behaviour that knowingly circumvents the scheme and therefore the protections the scheme extends to vulnerable people.

Alternative options considered include:

- Applying no offence to travelling outside of the ACT – this would render the scheme largely ineffective and not meet community expectations.

- Applying the criminal offence to interstate travelling – this is less specific to the purposes of the scheme and provides less clarity.
- A lower threshold for the mental element of the offence such as recklessness – this may inappropriately capture people who legitimately had no knowledge of the scheme.

### *Section 69 of the Australian Capital Territory (Self-Government) Act 1988 (Cth)*

The limitation on the right to movement discussed above engages section 69 of the *Australian Capital Territory (Self-Government) Act 1988 (Cth)* (Self-Government Act). Section 69 of the Self-Government Act mirrors, with reference to the ACT, the terms of section 92 of the Constitution. Section 92 of the Commonwealth Constitution provides that “trade, commerce, and intercourse among the States ... shall be absolutely free”. The term, “intercourse” refers to the movement of people between States.

The validity of restrictions of movement of people between the ACT and other States or Territory depends upon the purpose of the legislation and the proportionality of the offence to achieving that purpose. The justification set out above for limiting the right to freedom of movement under the HR Act, also demonstrates that the approach in the Bill is valid under section 69 of the Self-Government Act. The approach in the Bill to travelling outside the ACT for the purposes of restricted medical treatment is reasonably necessary and proportionate to the objective of preserving the integrity of the scheme and applying the scheme’s oversight to ACT residents.

### Section 22 – Rights in criminal proceedings

#### 1. Nature of the right and the limitation (s28(a) and (c))

If a doctor is charged with undertaking a restricted medical treatment in contravention of section 27, or a doctor or another person is charged with arranging or authorising such a treatment in contravention of section 28, a defence could be that the treatment was urgent. Sections 27(3) and 28(5) give the defendant – rather than the prosecution – the evidentiary burden of raising a reasonable possibility that the treatment was an urgent restricted medical treatment. Rights in criminal proceedings include the right, when charged with a criminal offence, to be presumed innocent until proved guilty according to law. This right is limited where an evidentiary burden is placed on a defendant if they are charged with an offence. In this circumstance, the defendant is under an evidential burden where they are required to raise evidence sufficient to raise a reasonable possibility that the treatment was an urgent restricted medical treatment.

## 2. Legitimate purpose (s28(b))

The legitimate purpose is twofold: to ensure that it is possible to undertake a treatment that is of great urgency without risking delay through the Bill's oversight procedures; but equally to ensure that the provision allowing such urgent treatments does not become a shield for non-urgent treatments that the Bill is specifically designed to regulate.

## 3. Rational connection between the limitation and the purpose (s28(d))

In order to both allow urgent treatments without committee oversight and to ensure the category of urgent restricted medical treatment is not misused, there must be a mechanism by which the urgency is required to be demonstrated, where a restricted medical treatment is found to have been performed without approval of a treatment plan under Part 3 of the Bill. Without such a mechanism, there would be no way to establish the legality or otherwise of the treatment.

## 4. Proportionality (s28 (e))

Placing an evidential burden on a defendant is justified where this is reasonable, necessary and proportionate in pursuit of a legitimate objective. This may be the case where the elements the defendant is being asked to prove are uniquely within the knowledge of, and capable of being established by, the defendant, and in all the circumstances it would be unreasonable for the prosecution to establish these elements.<sup>61</sup>

In the case of the offences in the Bill, a defendant will be uniquely placed to demonstrate why the particular medical treatment they undertook, arranged or authorised was urgent. They will have knowledge of the prescribed person's variation, health circumstances and the reasons an urgent treatment was sought. They are therefore the appropriate people to set out this information, should it be relevant because a charge is being brought under the offence provisions.

For the offence of arranging or authorising a treatment that, if it were performed, it would be in contravention of section 27, additional protection is provided to a defendant by requiring a mental element of knowledge of the regulatory scheme. This is intended to ensure that a person can only be convicted of the offence if they can be shown to have been aware of the scheme that they were circumventing. This is considered a prudent safeguard for an offence in a context where affected people may have moved into the Australian Capital Territory some time after they have established a relationship with a treating team outside the Territory and are not in contact with Territory health professionals. While they are required to comply with

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<sup>61</sup> ACT Government Justice and Community Safety Directorate, *Factsheet: Rights in criminal proceedings – Section 22 Human Rights Act 2004*, [https://www.justice.act.gov.au/\\_data/assets/pdf\\_file/0019/2072431/Fact-Sheet-O-s-22-Rights-in-criminal-proceedings-Human-Rights-Education.pdf](https://www.justice.act.gov.au/_data/assets/pdf_file/0019/2072431/Fact-Sheet-O-s-22-Rights-in-criminal-proceedings-Human-Rights-Education.pdf)



the scheme, and while there will be systems in place to make them aware of it, knowledge of the scheme should be required as an element of proving the offence of deliberately circumventing it.

## Variation in Sex Characteristics (Restricted Medical Treatment) Bill 2023

### *Human Rights Act 2004 - Compatibility Statement*

In accordance with section 37 of the *Human Rights Act 2004* I have examined the **Variation in Sex Characteristics (Restricted Medical Treatment) Bill 2023**. In my opinion, having regard to the Bill and the outline of the policy considerations and justification of any limitations on rights outlined in this explanatory statement, the Bill as presented to the Legislative Assembly **is** consistent with the *Human Rights Act 2004*.

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Shane Rattenbury MLA  
Attorney-General

## **CLAUSE NOTES**

### **Part 1 Preliminary**

#### **Clause 1 Name of Act**

This clause provides that the name of the Act is the *Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023* (the Act).

#### **Clause 2 Commencement**

This clause provides for the Act to be commenced six months after the Act's notification day, other than clause 10 and part 4, which will be commenced 18 months after the Act's notification day.

#### **Clause 3 Dictionary**

This clause provides for the dictionary located at the end of the Act.

#### **Clause 4 Notes**

This clause explains that notes are for explanatory purposes only and do not form part of this Act.

#### **Clause 5 Offences against Act—application of Criminal Code etc**

This clause explains that other legislation applies in relation to offences against this Act.

#### **Clause 6 Object of Act**

This clause sets out the object of the Act.

The criteria in clauses 13 to 16 cover areas in which it is known that rights of people with a variation in sex characteristics in relation to restricted medical treatment have not been upheld.

### **Part 2 Object and important concepts**

#### **Clause 7 Meaning of *variation in sex characteristics***

This clause defines the terms 'variation in sex characteristics' and 'sex characteristics'.

#### **Clause 8 Meaning of *restricted medical treatment***

This clause defines the term 'restricted medical treatment'.

## **Clause 9     Meaning of *prescribed person***

This clause defines the term ‘prescribed person’ in relation to restricted medical treatment.

Subclause 16(a) is related to clause 9(b)(ii). Subclause 16(a) requires the committee to be satisfied that there is sufficient evidence that reasonable steps have been taken in assessing that a child does not have decision-making capacity in relation to the proposed treatment.

If a child does have the required decision-making capacity, the child will provide personal consent, the treatment will not meet the definition of a restricted medical treatment and no application will be required.

## **Part 3           Assessment of treatment plans**

### **Division 3.1 Applying for approval of treatment plans**

#### **Clause 10    Requirement for treatment plans to be approved**

This clause requires that restricted medical treatment is only undertaken on a prescribed person in accordance with an approved treatment plan and any condition applying to the plan. The clause notes that failure to meet this requirement may give rise to an offence.

Subclause 2 provides an exception for urgent restricted medical treatment, as defined in the dictionary.

#### **Clause 11    Application for approval of treatment plan**

This clause allows a person to apply to the assessment board for approval of a general treatment plan or an individual treatment plan. It establishes that a general treatment plan is for a class of prescribed people – for example all prescribed people with a particular variation in sex characteristics, or all prescribed people who have a variation in sex characteristics and are proposed to receive a particular type of restricted medical treatment. An individual treatment plan is for a single prescribed person.

The clause sets out which people may apply for approval of a treatment plan and what information the application must include. The clause requires the president to give a copy of the application to the public advocate.

The public advocate may rely on functions in other legislation (for example the *Human Rights Commission Act 2005*) and exercise their discretion to decide whether or not and how to engage with applications.

## **Division 3.2 Assessment of treatment plans**

### **Clause 12 Assessment committee**

This clause requires the president to appoint assessment board members to an assessment committee to decide an application. The appointment must occur as soon as practicable and not more than 14 days after receiving an application. The president must appoint one assessment board member from each of the five categories identified in section 31(1)(b). The president may appoint themselves for the human rights category.

### **Clause 13 Assessment criteria – general and individual treatment plans**

The policy objectives of this clause are to: ensure that restricted medical treatment is only undertaken on a prescribed person if there is sufficient evidence that the person would suffer significant harm if treatment did not take place; and to place as few restrictions as appropriate on the ability to make future decisions about the person's sex characteristics.

This clause sets out the criteria an assessment committee must use when making a decision in relation to a general or individual treatment plan. The committee must be satisfied that there is sufficient evidence to fulfil each criteria.

Subclause (1)(a) requires assessment of the likelihood of the person or people to whom the plan applies suffering significant physical or psychological harm. The criterion is met if it is reasonably likely that the prescribed people will suffer that harm without the treatment or an alternative treatment.

Whether something is “reasonably likely” is for a committee to determine in the context of the health considerations placed before it. Whether something is reasonably likely is intended to mean “an event ...which is real – not fanciful or remote”.<sup>[1]</sup> It is intended that a committee will consider the seriousness of the harm which might be suffered without treatment, recognising that the risks associated with either undertaking or not undertaking a restricted medical treatment can vary significantly in magnitude, from cosmetic appearance that may have little or no bearing on a person's physical health, through to risks that may relate to possibility of serious illness or death.

The intention of the harm assessment criterion is to focus scrutiny on the sufficiency of evidence for the proposed medical intervention. The committee must not approve the proposed treatment if there is insufficient evidence that significant physical or psychological harm will be suffered by the prescribed person if the treatment were

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<sup>[1]</sup> *Department of Agriculture and Rural Affairs v Binnie* [1989] VR 836, Marks J at page 842.

not undertaken. Sections 14 and 15 set out matters that the committee may or must not consider in assessing if significant harm is reasonably likely to occur.

Subclause (1)(b) requires the committee to be satisfied there is sufficient evidence that alternative treatment options have been sufficiently considered.

Subclause (1)(c) requires a comparison of the proposed treatment against alternative treatments that are as effective as the proposed treatment, taking into account the primary harm and any associated harm. The criterion is met if the proposed treatment, compared to those alternative treatments, is no more restrictive of the ability to make a decision about a prescribed person's sex characteristics in the future than any satisfactory alternative treatment option.

The intention of subclauses (1)(b) and (c) is to ensure other reasonable options have been sufficiently explored, so that the assessment committee can be satisfied that future options have been kept open as far as possible, while also satisfactorily alleviating the significant harm.

Subclauses (2) and (3) define key terms for clause 13.

#### Example scenario for clause 13

An application is received seeking approval for treatment A. The committee considers that it is reasonably likely that a prescribed person would suffer significant harm (through suicide/self-harm) if they do not receive treatment. Evidence is provided that treatment A would avoid the significant harm. However, it will significantly reduce future treatment options. The committee seeks further information from expert bodies using its powers under section 18, supplying copies of the information to the applicant under section 20. It requests information from those bodies about whether the provision of intensive psychosocial support (treatment B) would be an effective treatment option for the prescribed person. After considering further information the committee is satisfied that treatment B would be as effective as treatment A for managing the risk of suicide and self-harm, and does not involve other risks of harm. The committee considers that treatment B allows more future choices about the person's sex characteristics. The committee, therefore, cannot approve treatment A.

#### **Clause 14 Assessment of significant harm – children**

This clause provides guidance to the committee for how to assess whether it is reasonably likely that a child would suffer significant harm as required by clause 13(1)(a).

Subclause (a) requires the committee, when considering an individual plan, to consider the wishes of the child who is going to undergo treatment. This allows the committee to consider the relationship between the proposed treatment and the

preferences of the child themselves. Clause 16 sets out related considerations for the child's wishes.

Subclause (b) applies only to children, for both individual and general treatment plans. It requires the committee to set aside any evidence that the treatment needs to be undertaken for the purpose of reducing discrimination or stigmatisation or a perceived risk of it. This extends special protection to the child by virtue of them being a child. The intent is that a treatment plan cannot be approved when the sole evidence offered in support of treatment is that it is to reduce discrimination, stigmatisation, or a perceived risk of it. However, there may be evidence of other causes of psychological harm or concerning the child's mental health to support that same proposed treatment. Evidence about the child's mental health as it relates to other aspects of their life or their body is relevant and can be considered.

### **Clause 15 Assessment of significant harm – adult subject to guardianship order**

This clause provides guidance to the committee for how to assess whether it is reasonably likely that an adult subject to a guardianship order would suffer significant harm as required by clause 13(1)(a).

Subclause (a) requires the committee, when considering an individual plan, to consider the wishes of the adult who is going to undergo treatment. This allows the committee to consider the relationship between the proposed treatment and the preferences of the person themselves. Clause 16 sets out related considerations for the person's wishes.

Subclause (b) applies only to adults, for both individual and general treatment plans. It requires the committee to set aside any evidence that the treatment needs to be undertaken for the purpose of reducing discrimination or stigmatisation or a perceived risk of it. The intent is that a treatment plan cannot be approved when the sole evidence offered in support of treatment is that it is to reduce discrimination, stigmatisation, or a perceived risk of it. However, there may be other evidence of psychological harm more generally or the adult's mental health to support that same treatment. Any evidence about the adult's mental health as it relates to other aspects of their life or their body is relevant and can be considered.

However, if the adult has communicated a wish to have the treatment undertaken, the requirement to disregard the evidence set out in subclause (b) does not apply. This allows the assessment committee to give greater weight to the adult's wishes.

### **Clause 16 Assessment criteria – individual treatment plans**

This clause provides additional criteria that an assessment committee must use when making a decision on individual treatment plans. The committee may only approve an individual treatment plan if satisfied the applicant has provided sufficient evidence to the committee to satisfy each criterion set out in clause 16. The clause

16 criteria are about engagement in decision-making about the treatment by the person who will undergo the treatment. Clause 16 is intended to support the person's full participation in decision-making, to the extent the person can.

The applicant is responsible for providing the evidence and therefore ensuring appropriate steps are undertaken. This is intended to encourage best practice in this area by the people responsible for providing care and decision-making. The committee is not responsible for undertaking the steps.

Subclause (a) applies to a treatment plan for a child. It requires the committee to be satisfied that the applicant has provided sufficient evidence that reasonable steps have been taken in assessing that the child does not have decision-making capacity in relation to the proposed treatment. The clause does not require the committee to assess whether or not the child has decision-making capacity. This will sit, under existing law, with a treating doctor responsible for the decision to treat. The committee is providing oversight of the process. A robust assessment of decision-making capacity is important, as the Scheme will not be enlivened if a child has decision-making capacity in relation to the proposed treatment, as explained above at clause 9.

Subclause (b) requires the committee to be satisfied that the applicant has provided sufficient evidence that the prescribed person has been given or had access to sufficient information about the matters listed in (1)(b)(i)-(iv), in a way that is consistent with the prescribed person's ability to understand the information.

Subclause (c) requires the committee to be satisfied that the applicant has provided sufficient evidence that the prescribed person has been given or had access to appropriate support to assist in understanding the information mentioned in (1)(b). The intention is to ensure support is provided to make the information accessible to the person consistent with their cognitive abilities.

Subclause (d) requires the committee to be satisfied that the applicant has provided sufficient evidence that each decision-maker for the prescribed person has been given or had access to sufficient information about the matters listed in (b). The intention is to ensure that information is being provided both to the person being treated, and their decision-makers, typically parents or guardians. The appropriate form and content of the information will typically be different for each. This subclause is also intended to ensure that applicants have considered what efforts may be needed to deliver information effectively to decision-makers for the prescribed person, for example where English is not their first language.

Subclause (e)(i) requires the committee to be satisfied that the applicant has provided sufficient evidence that the prescribed person has received appropriate support to participate in decision-making and to communicate their wishes freely. The intention is to ensure support is provided to make participation accessible to the person consistent with their cognitive abilities.



Subclause (e)(ii) requires the committee to be satisfied that the applicant has provided sufficient evidence that any wishes the prescribed person has communicated in relation to the proposed treatment or their variation in sex characteristics have been appropriately considered, taking into account the prescribed person's cognitive ability. It will be the committee's responsibility to assess who is responsible for considering the person's wishes and what constitutes appropriate consideration for the specific circumstances of the application. This will include consideration of the evolving capacity of children.

The note explains that clause 23(2)(a) means that a condition of an approved general plan is that the person undertaking the treatment ensures that paragraph (a) to (e) of clause 16 are satisfied.

### **Clause 17 Ministerial guidelines about assessment criteria**

This clause provides that the Minister may make guidelines about the matters that an assessment committee must or may consider under clauses 13, 14, 15 and 16. The guidelines may also provide other guidance to assist an assessment committee or internal review committee to exercise their functions under the Act.

### **Clause 18 Operation of assessment committee**

This clause provides that an assessment committee may conduct an assessment of an application in the way it considers appropriate. The clause provides illustrative examples of ways the committee may inform itself.

Subclause (2) provides a non-exhaustive list of the individuals or bodies the assessment committee may consult in relation to an application. This does not limit the assessment options available to the committee.

This ensures the committee has the appropriate flexibility to adapt each assessment to the circumstances of the application and appropriately inform itself about the specific matters raised by each application. The committee will be able to adopt person-centred approaches to assessing applications.

Subclause (3) requires the committee to obtain written consent of a decision-maker (as defined in the dictionary) before disclosing the identity or identifying information about a prescribed person.

### **Clause 19 Request for more information**

This clause allows an assessment committee to request, in writing, an applicant to give the committee information that the committee reasonably needs to decide the application. The purpose of this discretion is to ensure the committee has sufficient information to reach a view about the matters in clauses 13 to 16.

This clause provides flexibility for the committee to request further details about the proposed treatment plan or alternative options available. It may also involve the

applicant engaging further with the prescribed person and providing information about the outcome, for example arranging for additional information to be available to the prescribed person or arranging for the prescribed person's views to be further explored.

Subclause (2) allows a committee to refuse to consider the application further if the information is not provided within the period stated in the request. This decision is an internally reviewable decision under Part 6.

#### **Clause 20 Applicant to be given any other information obtained by committee**

This clause requires an assessment committee to provide the applicant with a copy of: information relied upon by the committee; any information received through consultation; or any submission received and give the applicant a reasonable opportunity to consider the information and make any changes to their application. This is an important element of ensuring the applicant is provided procedural fairness. It also assists the committee to be informed from multiple perspectives.

It will be the committee's responsibility to identify the length required for a reasonable period of time. This will be different depending on the complexity of the information or submission and the impact it may have on the application.

### **Division 3.3 Assessment of general treatment plans**

#### **Clause 21 Public consultation**

This clause requires the assessment committee to conduct public consultation for each general treatment plan and give a consultation notice. The purpose of consultation is to ensure that when one organisation or group proposes a general treatment plan, all people with interest and expertise have an opportunity to review and comment on it.

Subclause (2) provides that a consultation notice must state that anyone may give a written submission about the general treatment plan and provide a consultation period with a minimum of 30 days. The assessment committee may choose to provide a longer consultation period.

The assessment committee must include the general treatment plan and any relevant supporting information included in the application in the consultation notice.

Subclause (4) provides that the committee must publish the notice on an ACT government website and give it to the relevant entities identified in subclause (6). The entities identified in subclause (6) are public officials who perform functions under other legislation that may be relevant to an application under this Bill. This clause introduces no obligations on the relevant entities. The relevant entities may rely on functions in other legislation and exercise their discretion to decide whether or not and how to engage with applications.

Subclause (5) prohibits the assessment committee from including identifying information about any prescribed persons or their decision-maker. This reflects that the consultation is both public and for a type of plan that is not intended to approve care for a particular individual. It protects the privacy of people with variations in sex characteristics or their families who might have interacted with the board in the course of advocating for, or proposing, a general treatment plan.

Subclause (6) identifies the relevant entities for the purposes of subclause (4).

## **Clause 22 Public consultation submissions**

This clause allows anyone to provide a written submission to the committee in response to a consultation notice during the consultation period.

Subclause (2) requires the committee to publish the submission on an ACT government website.

Subclause (3) prohibits the committee, when publishing submissions from publishing identifying information about a prescribed person, unless it is consistent with that person's will and preferences. This protects the privacy of persons with variations in sex characteristics, particularly those who might in future be treated under the plan.

Subclause (3) also prohibits the committee from publishing any information the committee considers to be sensitive or prejudicial to an individual. This recognises that applications are likely to deal with sensitive information and requires the committee to exercise its judgement to avoid harm.

## **Clause 23 Deciding the application – general treatment plan**

This clause requires the assessment committee to consider any written submission received during the consultation period and either approve or refuse the application, in accordance with clause 13.

Subclause (2)(a) provides that if the committee approves a general treatment plan, the plan is subject to a condition that the matters mentioned in clause 16 (a) to (e) be satisfied before the restricted medical treatment is undertaken on a prescribed person.

The matters in clause 16 (a) to (e) are about engagement in decision-making about the treatment by the person who will undergo the treatment. Clause 16 is intended to support the person's full participation in decision-making, to the extent the person can. At the stage of committee consideration and approval of a general treatment plan, the individuals who will undergo treatment are not identified, therefore the clause 16 criteria cannot be assessed by the committee.

The intention of this clause is to require doctors to satisfy the criteria when providing care to an individual under the general treatment plan. Failure to satisfy the matters in clause 16 (a) to (e) when treating an individual under a general treatment plan,

may constitute an offence under clause 27 or be the basis for occupational discipline. The assessment committee will not be responsible for monitoring compliance with this condition.

Subclause 2(b) provides a discretion for the assessment committee to approve a general treatment plan subject to any other condition the committee considers appropriate. This provides the necessary flexibility to address the unique matters raised by each general treatment plan.

Subclause (3) requires the assessment committee to give a copy of its decision about a general treatment plan, and the reasons for it, to the applicant and the relevant entities identified in clause 21(6). The entities identified are public officials who perform functions under other legislation that may be relevant to an application under this Bill. This clause introduces no obligations on the entities. The entities may rely on functions in other legislation and exercise their discretion to decide whether or not and how to engage with decisions.

Subclause (4) provides that an approval of a general treatment plan is a notifiable instrument. This ensures that the final plan is available to the public and, in particular, to health professionals, people with variations in sex characteristics and their decision-makers. Subclause (4) also provides that an approval of a general treatment plan expires 5 years after the day it commences, and notes that an approval may be extended under clause 25(2)(a). An approval may also be reviewed under clause 24. The intention of the 5-year period is to provide an appropriate balance between giving healthcare providers, prescribed persons and decision-makers certainty about what treatments will be able to occur in the future as they plan their care, and maintaining the currency of the plan.

### **Division 3.4 General treatment plans – other matters**

#### **Clause 24 Review of approved general treatment plan**

This clause allows the board to initiate a review of an approved general treatment plan.

Subclause (1) provides the president with discretion to establish an assessment committee to review the general treatment plan at any time until the plan has expired.

Subclause (2) requires the assessment committee to revoke the general treatment plan if the committee is not satisfied there is sufficient evidence to meet the criteria in clause 13.

Subclause (3) requires the committee conducting the review to follow the same requirements as for the original assessment of an application for a general treatment plan. Subclause (3)(b) is qualified by the words ‘as far as is reasonably practicable’, recognising that it may not always be possible to contact the original applicant.

Subclause (4) requires an assessment committee to state the day that revocation of a plan takes effect. That day must be at least six months after the day the decision is made. The six-month time period provides time for healthcare providers, prescribed persons and decision-makers to plan for changes to care of the kind that was previously covered by a general care plan. This could include seeking new individual treatment plans, or supporting an application for a different general treatment plan to cover prescribed persons who may have been receiving treatment consistent with the general treatment plan that is being revoked.

### **Clause 25 Expiry of approved general treatment plan**

This clause provides notification processes for expiring general treatment plans and a transition process for new treatment plans that substantially correspond to an expiring treatment plan.

## **Division 3.5 Assessment of individual treatment plans**

### **Clause 26 Deciding the application – individual treatment plan**

This clause requires the assessment committee appointed under clause 12 for an application for an individual treatment plan to either approve or refuse the application, in accordance with the criteria in clauses 13 to 16.

Subclause (2) provides discretion for the assessment committee to approve an individual treatment plan subject to any condition the committee considers appropriate. This provides the necessary flexibility to address the unique matters raised by each individual treatment plan.

Subclause (3) requires the assessment committee to give a copy of its decision about an individual treatment plan and the reasons for it to the applicant, parent or guardian and the public advocate. This clause introduces no obligations on the public advocate. The public advocate may rely on functions in other legislation (for example the *Human Rights Act 2005*) and exercise their discretion to decide whether or not and how to engage with decisions.

Subclause (4) provides that an approval for an individual treatment plan is valid for a period of up to 3 years. This gives the committee discretion to tailor an approval to the timeline needed for an individual's treatment, and to reflect any appropriate timeline for future treatments to be considered by the committee consistent with the potential for changing or evolving capacity and views of a protected person.

## **Part 4 Offences**

### **Clause 27 Offence – undertaking restricted medical treatment without approval**

This clause provides that it is an offence for a person to undertake a restricted medical treatment on a prescribed person, not in accordance with an approved treatment plan or any condition applying to the plan.

It does not matter if a parent, guardian or ACAT consents to the restricted medical treatment.

The offence does not apply to urgent restricted medical treatment as defined in the dictionary, noting that the defendant has an evidential burden in relation to whether the treatment was urgent restricted medical treatment.

### **Clause 28 Offence – arrange or authorise unapproved restricted medical treatment**

Subclause (1) provides that it is an offence for a person to take a prescribed person outside the ACT for the purpose of having restricted medical treatment undertaken on the prescribed person or to otherwise arrange for the treatment to be undertaken, if the person knows that if the restricted medical treatment were undertaken on the prescribed person in the ACT it would be an offence against clause 27. It does not matter if a parent, guardian or ACAT consents to the restricted medical treatment.

Subclause (2) provides that it is an offence for a decision-maker to consent to a restricted medical treatment being undertaken on the prescribed person, if the decision-maker knows that if the restricted medical treatment were undertaken on the prescribed person in the ACT it would be an offence.

For both offences in clause 28, it does not matter if the restricted medical treatment was not undertaken on the prescribed person or was undertaken in the ACT or elsewhere.

The offences do not apply to urgent restricted medical treatment as defined in the dictionary, noting that the defendant has an evidential burden in relation to whether the treatment was urgent restricted medical treatment.

The intention of the offences is to prevent people from deliberately circumventing the scheme, acknowledging the serious harm that individuals have experienced from similar treatments in the past.

## **Part 5 Restricted Medical Treatment Assessment Board**

### **Clause 29 Establishment of Restricted Medical Treatment Assessment Board**

This clause establishes the Restricted Medical Treatment Assessment Board.

## **Clause 30 Functions of assessment board**

This clause identifies the functions of the assessment board.

Paragraph (b) provides that one of the functions is to advise the Minister about and make recommendations on which variations in sex characteristics should be covered by this Act. This enables the board to provide advice in relation to whether changes should be made to regulations under clause 7(1), changing which variations in sex characteristics may be excluded from the requirements of the approval processes. The ability to fulfil this function is supported by the reporting requirements in clause 43.

## **Clause 31 Membership of assessment board**

This clause allows for the appointment of members to the assessment board.

Subclause (1) requires the Minister to appoint a minimum of eleven members to the assessment board. The Minister must appoint a president plus a minimum of two people to represent each category identified in subclause (1)(b)(i) to (v).

The requirement for a minimum of two people to represent each category is intended to meet the requirement in subclause 38(3), to not appoint to an internal review committee any of the members involved in the original reviewable decision.

Subclause (2) requires the Minister to consult the Ministers responsible for the *Health Act 1993* and the *Human Rights Act 2004* before appointing a person to be the president or a member of the assessment board. This recognises the connections between the functions of the board and the functions of these Acts.

Subclause (3)(a) requires the Minister to be satisfied that the president has the qualities and experience necessary to exercise their functions under this Act, including to be an assessment committee or internal review committee member with qualifications or experience in human rights.

Subclause (3)(b) requires the Minister to be satisfied that each member has qualifications or experience in the category for which they are appointed.

Subclause (4) requires at least one person across the five categories to be a person with a variation in sex characteristics.

Subclause (5) provides that an appointment must be for five years or less.

## **Clause 32 Ending appointments**

This clause provides the Minister with discretion to end a member's appointment for misconduct, or if the member is convicted or found guilty of an indictable offence, whether the offence was committed in the ACT or elsewhere, or if the member is unable to exercise the members functions. Indictable offences are relatively serious offences involving imprisonment of more than 2 years.

The Minister can use the discretion to not terminate an appointment if the Minister is satisfied the conviction is irrelevant to the continuing appointment of the member.

The intention of this clause is to ensure that members maintain their suitability to be appointed to the position.

### **Clause 33 Arrangements for staff and facilities**

This clause allows the president to arrange with the head of service to use the services of a public servant or territory facilities. The intention is that the head of service may provide support to the president to fulfil the functions of the assessment board.

### **Clause 34 Consultants for assessment board**

This clause allows the president to engage consultants to assist an assessment committee in the exercise of its functions.

## **Part 6 Notification and review of decisions**

### **Clause 35 Definitions – pt 6**

This clause sets out definitions for Part 6, Notification and review of decisions. The definitions include identifying which decisions of the board can be subject to an internal review. These are:

- A refusal to consider further an application, because the applicant has not responded on time to the committee's requests for more information;
- A refusal of a treatment plan application;
- The imposing of a condition on a treatment plan; and
- The revoking of a general treatment plan following a review under clause 24.

### **Clause 36 Internal review notices**

This clause requires an assessment committee to give an internal review notice to an interested party if the committee makes an internally reviewable decision.

Interested parties include the applicant, each decision-maker for the prescribed person and the public advocate.

The public advocate may rely on functions in other legislation (for example the *Human Rights Commission Act 2005*) and exercise their discretion to decide whether or not and how to engage with an internal review notice.

### **Clause 37 Application for internal review**

This clause allows an interested party to apply in writing for review of an internally reviewable decision within 28 days of receiving the notice. The clause sets out the requirements for an application for internal review.



### **Clause 38 Appointment of internal review committee**

This clause requires the president to establish an internal review committee as soon as practicable and not more than 14 days after receiving an application to review the internally reviewable decision.

The clause sets out the requirements for appointing members to the internal review committee.

### **Clause 39 Decision of internal review committee**

This clause requires the internal review committee to review the internally reviewable decision and make a decision as soon as is reasonably practicable and within 28 days after the first meeting of the committee. The internal review committee will exercise the powers of the original decision-maker.

The internal review committee must confirm, vary or replace the original decision. If the reviewable decision is not varied or replaced within the 28-day period, the decision is taken to have been confirmed by the internal review committee.

### **Clause 40 Reviewable decision notices**

This clause requires the internal review committee, if it makes a reviewable decision, to give a reviewable decision notice to each interested party. Clause 36 sets out who is an interested party.

### **Clause 41 Application for ACAT review**

This clause provides for external review to ACAT for an interested party.

### **Clause 42 Review by ACAT**

This clause requires ACAT to consider an application it receives to review a reviewable decision and confirm the decision or remit the matter to an internal review committee of the Restricted Medical Treatment Assessment Board for reconsideration in accordance with any direction or recommendation of the ACAT.

## **Part 7 Miscellaneous**

### **Clause 43 Reporting treatment in relation to sex characteristics**

This clause requires the doctor responsible for a reportable treatment to report to the president, within 3 months after starting the treatment, that the treatment has been undertaken and provide any information prescribed by regulation.

The intention of this clause is to develop an evidence base to inform the board's decision-making. It will also create an evidence base that will support future review of the functions of the Act under clause 47.

#### **Clause 44 Assessment board annual report**

This clause requires the president to prepare a report about the assessment board's operation during each financial year. The president must give the report to the Minister and publish it on an ACT government website.

The clause sets out information that the annual report must include. This will give the Minister and the broader community an understanding of how often the approval processes under the Bill are being used, and for what purpose.

The report must not include information that identifies a prescribed person or a decision-maker for the prescribed person or would allow a prescribed person's identity or the identity of a decision-maker to be worked out.

#### **Clause 45 Restricted medical treatment records**

This clause displaces the operation of the *Health Records (Privacy and Access) Act 1997* or the *Territory Records Act 2002* in relation to the length of time that a relevant record created in relation to restricted medical treatment or urgent restricted medical treatment undertaken on a prescribed person must be kept.

Despite anything to the contrary in the *Health Records (Privacy and Access) Act 1997* or the *Territory Records Act 2002* the relevant record must be kept until the later of the prescribed person's 45<sup>th</sup> birthday or seven years after the day the record is made.

Subclause (3) defines the terms 'health record' and 'relevant record'.

The intention of this clause is to require relevant records created in relation to restricted medical treatment or urgent restricted medical treatment undertaken on a prescribed person to remain available for a reasonable period of time to the person with a variation in sex characteristics. In the case of treatments performed during childhood, the retention period is longer than is currently required and is intended to support people with a variation in sex characteristics to be able to find out their restricted medical treatment history, particularly through the stage of life where they are most likely to seek to have children. This is intended to rectify problems where a person with a variation in sex characteristics has only become aware of having a medical history when experiencing fertility problems, at which point their records have no longer been retained.

#### **Clause 46 Regulation-making power**

This clause allows the Executive to make regulations for this Act.

Subclause (2) requires the Executive to consult the entities identified in subclauses (2)(a) to (f) prior to making a regulation for clause 7. The entities identified are public officials who perform functions under other legislation that may be relevant to a Regulation. This clause introduces no obligations on the entities. The entities may

rely on functions in other legislation and exercise their discretion to decide whether or not and how to engage in the consultation. The entities are the same as those identified for public consultation on general treatment plans under Division 3.3.

#### **Clause 47    Review of Act**

This clause requires the Minister to review the operation and effectiveness of the Act and present a report of the review to the Legislative Assembly as soon as practicable after the end of the Act's second year of operation.

#### **Dictionary**

The Dictionary sets out the definitions for this Act.