2024

THE LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

ELEVENTH ASSEMBLY

VARIATION IN SEX CHARACTERISTICS (RESTRICTED MEDICAL TREATMENT) AMENDMENT BILL 2024

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

Presented by Rachel Stephen-Smith MLA

VARIATION IN SEX CHARACTERISTICS (RESTRICTED MEDICAL TREATMENT) AMENDMENT BILL 2024

The Variations in Sex Characteristics (Restricted Medical Treatment) Amendment Bill 2024 (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 amends the Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023 (the Act) to put in place a twelve-month transitional arrangement to enable treatment for 'prescribed persons' who have already received treatment in relation to their variation in sex characteristics. The transitional period applies for twelve months from the commencement of section 10 and Part 4 of the Act (the transitional period). The transitional arrangement will only apply to prescribed persons who, prior to the transitional period, have received medical treatment in relation to their variation in sex characteristics (the affected cohort). During the transitional period, the affected cohort will be able to receive what would otherwise be a 'restricted medical treatment' under the Act without requiring an approved treatment plan to be in place. For an explanation of key terms under the Act such as 'restricted medical treatment' and 'prescribed person' see the explanatory statement for the Act.

From 23 December 2024, the Act will prohibit restricted medical treatments without a treatment plan approved by the oversight body, the Restricted Medical Treatment Assessment Board (the Board). Due to unanticipated issues in implementing the scheme it is not possible to have treatment plans in place for all members of the affected cohort prior to commencement of the relevant parts of the Act. This Bill will address risks to the physical and psychological wellbeing of those individuals if their treatment is halted or disrupted.

This Bill responds to the needs of prescribed persons who have received treatment in relation to their variation in sex characteristics prior to 23 December 2024, and who do not have an approved treatment plan in place under the Act. As of late November 2024, the affected cohort are all understood to be children who each have varied and complex clinical care needs, and require a range of ongoing treatment, some of which affects their sex characteristics.

Underlying principles of the Act

The Act was made with the object of protecting the rights and ensuring the wellbeing of people with a variation in sex characteristics in relation to restricted medical treatment (section 6). The Act provides assurance that decisions that trigger irreversible medical treatments affecting the sex characteristics of prescribed persons uphold the rights of those people.

The Act is underpinned by five principles developed by the Australian Human Rights Commission in its 2021 report *Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics.*¹ These principles are:

- *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.

Statutory oversight provided by the Board

To give effect to the principles of independent oversight, bodily integrity, children's agency, and precaution, the Act established the Board. The Board oversees decisions to undertake restricted medical treatment, through its review of treatment plans to ensure that a person's human rights and right to physical integrity are upheld. The Act supports these objectives through the requirement that assessment committees - comprising members of the Board - 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)).

¹ Australian Human Rights Commission, 2021, *Ensuring health and bodily integrity: towards a human rights approach for people born with variations in sex characteristics*, <u>https://humanrights.gov.au/intersex-report-2021#bIXcN</u>

- 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 Act also supports these principles by requiring assessment committees 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(1)(c)).

Review process of Board

Section 10 of the Act, which is due to commence on 23 December 2024, requires that all treatment plans for a prescribed person must be assessed and approved by the Board before a restricted medical treatment can be lawfully undertaken.

The decision-making and review process for treatment plans is a time and resource intensive process. It requires the integration of a broad spectrum of perspectives and expertise – from human rights, medicine, ethics, lived experience of a variation in sex characteristics, and psychosocial support – in order to undertake a holistic comparison of the harms associated with the proposed treatment and any alternative treatment options, and their effectiveness in mitigating the overall harm suffered by the prescribed person.

The process of development and approval of treatment plans is also an intensive process for the prescribed person and their family. To assess whether the prescribed person is not able to consent to the treatment themselves, and to ensure the prescribed person's views have been adequately taken into account in the development of an individual treatment plan, a sensitive and sometimes lengthy series of conversations with the prescribed person are required, alongside delivery of appropriate psychosocial supports. This process takes time and sensitivity, and if rushed can pose risks to the wellbeing of the prescribed person.

Whilst the process of consideration, development and approval of treatment plans is an intensive one, it was never the intention of the Act that the requirement for the Board to review treatment plans (section 10) would delay or prevent medically necessary treatment of a person that is consistent with the person's wishes.

Unanticipated issues in implementation

At the time the Act was passed, the regulatory approach to ensuring independent oversight of restricted medical treatments in relation to people without capacity was (and still is) nation and world leading. The scheme established by the Act responds to complex clinical environments, human rights issues, and ethical issues. The Act was designed to respond to this complexity, to allow a degree of flexibility in the regulatory approach, for example by providing power for the Executive to, following consultation, make regulations that move individual variations in sex characteristics within, or outside the authorisation scheme in the Act.

The staged commencement of the Act was intended to:

- avoid disruption to care of existing patients;
- ensure care decisions could be made for new patients;
- enable training to be provided to the healthcare workforce ahead of the legal requirement for approved treatment plans taking effect; and
- allow treatment plans to be developed to support care decisions once the Act's regulatory mechanisms became mandatory.

This was intended to be achieved by allowing a period of 12 months between the establishment of the Board, on 23 December 2023 (at which point treatment plans could be submitted) and the commencement of the regulatory provisions requiring authorisation of restricted medical treatments (23 December 2024).

While the Board has been established, and has started to receive treatment plans for consideration, the intent of the flexibility of design and staged implementation has not been fully realised. Once training commenced, it became apparent that approved treatment plans will be required for all patients, including current patients.

However, the intensive process required for the development and approval of treatment plans means the affected cohort will not be able to have a treatment plan approved before 23 December 2024 in respect of their current and upcoming treatment needs. The time and resources required to complete treatment plans for existing patients is significant. For example, there are challenges for clinicians and parents of existing patients in providing the mandatorily required evidence on decision-making capacity and information provision and support. Unlike new patients, this cohort do not have a formal capacity assessment or information provision and support documented (because these were not necessary when they were originally seen and treatment commenced). For this cohort, if a capacity assessment is needed, patients have to be contacted and brought in for an assessment outside the normal cycle of their medical consultations.

People in the affected cohort often have complex health needs, requiring complex treatment planning and pathways. Given the complexity of the treatment involved, even if treatment plans were able to be urgently developed and submitted to the Board, the Board would not have sufficient time to thoroughly consider those plans as required by the Act and to have the treatment plans approved prior to 23 December 2024.

'Urgent restricted medical treatment' under the Act

The Act does provide for urgent restricted medical treatments to continue to occur, without requiring a treatment plan, however, this mechanism in the Act does not resolve the circumstances of the affected cohort. To be excluded from the obligation

to comply with a treatment plan, a restricted medical treatment must meet the definition of urgency of the Act (section 3, Dictionary). Under the Act, an urgent restricted medical treatment is a restricted medical treatment to be undertaken urgently to save a prescribed person's life, prevent serious damage to the person's health, or prevent the person from suffering or continuing to suffer significant pain. The explanatory statement for the Act makes clear that the purpose of the provision was to allow only treatments required with great urgency.

For the affected cohort, although treatment may be necessary to prevent serious damage to their health, the treatments required are likely to be time critical rather than urgent to the degree required by the Act. For example, some treatments for a person with a variation in sex characteristics may need to be administered to the patient within a certain developmental window to achieve the desired outcome, or alternatively, need to be administered consistently over a long period without disruption. These treatments may not be necessary to prevent significant pain or urgent threat to life, but are still time critical, and failure to access, halting or disruption of treatment may pose serious risks to the physical and psychological wellbeing of those children.

Therefore, the exemptions in the Act for "urgent restricted medical treatment" do not resolve the risks for the affected cohort.

Main features of the Bill

The Bill introduces a new 12-month transitional arrangement, which will permit further treatments of a person with a variation in sex characteristics who has received medical treatment as of 23 December 2024, the date on which section 10 and part 4 of the Act commence (see new section 50). A restricted medical treatment will only be authorised under the new transitional arrangement where, prior to 23 December 2024, the person has received medical treatment in relation to their variation in sex characteristics.

Such medical treatment includes a surgical or medical procedure or treatment (including the prescription or administration of a drug) and need not be a restricted medical treatment (see new section 50(3)). The transitional arrangements will only apply in respect of section 10 (Requirement for treatment plans to be approved) and part 4 (Offences). This means that restricted treatment could still legally occur under section 10 without an approved treatment plan, and no criminal offence would occur under part 4. However, during the transitional period the rest of the Act will continue to apply to the affected cohort, as it has since 23 December 2023.

This transitional period will allow the Board to consider and assess treatment plans for the affected cohort and will provide the necessary time for treatment plans to be developed in respect of the affected cohort.

This will in turn give effect to the underlying principles of the Act. For the affected cohort, consistent with the children's agency principle, the transitional period will ensure that there is sufficient time for the views of those children to properly and sensitively be considered and given due weight. During the transitional period,

consistent with the bodily integrity principle, treatments which already reflect the prescribed person's wishes can continue to be provided to eliminate the risk that legal restrictions would stop or disrupt ongoing treatment. To maximise the Board's independent oversight of the affected prescribed people, the transitional arrangements will only apply for the period of 12 months, to facilitate the development and approval of treatment plans by the Board.

CONSULTATION ON THE PROPOSED APPROACH

Given the urgency with which this Bill has been brought, it has not been possible to consult with external stakeholders in relation to the Bill's development.

The ACT Health Directorate (ACTHD) has worked closely with Canberra Health Services (CHS) to support the ongoing care of people currently receiving treatment for their variation in sex characteristics and in the development of the policy approach for this Bill. CHS clinicians have been able to advise on the experience of their patient cohort and the effects of the changes on them. ACTHD has also been working closely with the Board in respect of the underlying issues addressed in this Bill, including in relation to the Board's requirements to ensure timely and appropriate review of individual treatment plans.

ACTHD has also consulted with Justice and Community Safety Directorate in relation to the human rights compatibility of the proposed amendments, as well as the Office of LGBTQIA+ Affairs and the Health Services Commissioner in the ACT Human Rights Commission.

CLIMATE IMPACT

This Bill does not have any climate impact.

CONSISTENCY WITH HUMAN RIGHTS

The proposed Bill has been carefully considered in the context of the objects of the *Human Rights Act 2004* (HR Act). Any limitations on human rights are justifiable as reasonable limits set by laws in a free and democratic society, as required by section 28 of the HR Act. Importantly, the Bill also supports and strengthens protection of several rights under the HR Act. The human rights limitations that this Bill creates are proportionate to and the least restrictive approach to achieve the overall policy objective of this Bill.

Rights engaged

The Bill engages the following rights under the HR Act:

- Section 8 Right to equality and non-discrimination (promoted and limited)
- Section 9 Right to life (promoted)

- Section 10 Protection from torture and cruel, inhuman or degrading treatment etc (promoted and limited)
- Section 11 Right to protection of the family and child (promoted and limited)
- Section 12 Right to privacy (promoted and 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.

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 that people are not subjected to discrimination by others. This may require the Government to take affirmative action or positive measures (also known as 'special measures') to diminish or eliminate conditions which could perpetuate discrimination.

The Act promotes the right to equality and non-discrimination by establishing 'special measures' to ensure that people with variations in sex characteristics are protected from harm and that non-discriminatory decisions are made about medical intervention for people with a variation in sex characteristics. The Act creates those special measures by establishing a Board (section 29), comprising people with expertise related to relevant aspects of care decision-making for prescribed persons (section 31), and requiring that restricted medical treatment on a prescribed person can only occur in accordance with a treatment plan approved by the Board (section 10). This ensures that prescribed persons are not subject to medical treatment decisions based on reasons which would not be applied to a person without a variation in sex characteristics.

Due to the unanticipated issues with implementation of the Act in the 12 month commencement period, as set out above, if section 10 and Part 4 of the Act were to commence on 23 December 2023, there is a risk that children who were not able to have their treatment plans approved by the Board prior to this date will be unable to legally access medically necessary restricted medical treatments in relation to their variation in sex characteristics.

This would have a significant discriminatory effect on this cohort of prescribed people, who would become unable to access necessary health care. The result of being unable to access treatment would mean that this group of people is likely to face significant risks to their physical and psychological wellbeing. This significant

discriminatory impact comes within the context of the overall significantly worse health outcomes experienced by LGBTIQA+ Canberrans when compared with their peers.²

The Bill will promote the right to equality and non-discrimination by ensuring that the affected cohort can continue to obtain the treatment required, including restricted medical treatments, for the transitional period. This will allow sufficient time to give effect to the purpose of the Act, and for applications for treatment plans to be made and approved by the Board. This will ensure effective oversight of the restricted medical treatments for this cohort from the end of the transitional period.

Section 9 - Right to life

Section 9(1) of the HR Act recognises that everyone has the right to life and that no one may be arbitrarily deprived of life. The right to life requires the ACT Government to safeguard life where there may be a real and immediate direct or indirect risk to life.

The Bill will allow the affected cohort to legally access medically necessary restricted medical treatments in relation to their variation in sex characteristics whilst treatment plans are prepared and considered by the Board during the transitional period. This will help to protect the physical and psychological wellbeing of the affected cohort, who will be able to continue to access restricted medical treatments.

Section 11 - Right to protection of the family and child

Section 11 of the HR Act provides that the family is the natural and basic group unit of society and is entitled to be protected by society. Section 11(2) provides that every child has the right to the protection needed by the child because of being a child, without distinction or discrimination of any kind.

The rights of children are interpreted by reference to the rights contained in the Convention on the Rights of the Child.³ Overall, the convention requires that the best interests of the child must be a primary consideration in any decision that affects the child. Article 24 of the Convention on the Rights of the Child recognises the right of the child to the enjoyment of the highest attainable standard of health, including access to facilities for the treatment of illness and rehabilitation of health. The Convention requires that all appropriate measures are taken to ensure the provision of necessary medical assistance and health care to all children.

The Bill will promote the right of children to special protection, by ensuring that each child in the affected cohort can continue to obtain the treatment they require in their best interests, including restricted medical treatments, for the transitional period. This will allow sufficient time for applications for treatment plans to be made and approved by the Board, to ensure effective oversight of the restricted medical treatments for this cohort from the end of the transitional period.

² ACT Health Directorate, 2021, LGBTIQ+ Health Scoping Study report.

³ United Nations Convention on the Rights of the Child, November 20, 1989, <u>https://www.ohchr.org/en</u>.

Rights Limited

This Bill will delay some of the protections of the Act, many of which were designed to promote the rights of protected persons by establishing special measures to protect those rights. The limitations on these rights are intended to avoid a worse outcome for the affected cohort of being unable to legally access medically necessary treatment, or having their treatment disrupted. The ways in which the Bill will limit the rights sought to be promoted by the Act are detailed below.

Section 8 - Right to equality and non-discrimination

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

The right to equality and non-discrimination in the HR Act provides that everyone is entitled to enjoy their rights without discrimination of any kind.

This includes certain positive obligations to promote the right to equality and nondiscrimination by having laws and measures in place to ensure people are not subjected to discrimination by others, such as the special measures put in place by the Act. Ensuring non-discriminatory decisions are made about medical intervention for people with variations in sex characteristics requires special measures to assure the right to equality and non-discrimination is upheld. 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".⁴

The Bill limits the right to equality and non-discrimination because it delays the onset of the special measures at section 10 and part 4 of the Act for the affected cohort. Specifically, the Bill delays the mandatory oversight of the Board of restricted medical treatments for the affected cohort, which was designed to protect persons with a variation in sex characteristics who might be subjected to harmful practices in connection with treatments for their variation in sex characteristics. Therefore, the right to equality and non-discrimination is limited as the affected cohort will not benefit from the protection of the special measures during the transitional period.

Further, the right to recognition and equality before the law includes the right to equal protection of the law without discrimination. The right to equality before the law is limited because it treats people who received medical treatment prior to December 2024 differently under the law to people who will commence treatment after December 2024, by not affording them the same protections under the Act from restricted medical treatment without an approved treatment plan.

⁴ Androgen Insensitivity Support Syndrome Support Group Australia et al, 2017, Darlington Statement, <u>Darlington Statement – Intersex Human Rights Australia</u>

2. Legitimate Purpose (s28(b))

The objective of the Bill as it limits the special measures established by the Act, is to ensure that the affected cohort continues to receive time critical and necessary medical care. The affected cohort are currently receiving medical treatment in relation to their variation in sex characteristics, which may or may not be restricted medical treatment. Continued or further treatment may be necessary to ensure they do not suffer physical or psychological harm. The affected cohort are at risk of suffering serious physical or psychological harm if they are not legally able to receive treatment within appropriate timeframes or if they are required to discontinue treatment while treatment plans are developed.

For the affected cohort, the harm suffered may not fall within the definition of 'urgent restricted medical treatment' and so the Act, without amendment, would operate to cause the affected cohort to interrupt, delay or cease any ongoing or planned restricted medical treatment. The affected cohort would also not be able to receive care in another jurisdiction, as arranging that care would also be an offence under the Act (section 28).

Current medical best practice endeavours to ensure that a person's treatment is not undertaken in a manner which is discriminatory, and is consistent with that person's wishes. The review of treatment plans by the Board is intended to ensure discriminatory treatment practices are prevented in every case and any restricted medical treatment meets the requirements set out in the Act. The Board thereby provides an additional layer of assurance that the rights of persons with a variation in sex characteristics are protected.

However, as identified in the overview, it was never the intention of the Act that the requirement for the Board to review treatment plans (section 10) would delay or inhibit medically necessary treatment of a person, where that is consistent with the person's wishes and the criteria in the Act.

Given the current challenges faced by health practitioners and the Board to prepare and review treatment plans for the existing cohort of patients – which have only recently become apparent – restricted medical treatments which may be considered to be acceptable by the Board and consistent with the person's wishes could be prevented from occurring. These treatments could be time-critical depending on the person's age, onset of puberty and the person's particular variation in sex characteristics.

Any delay, interruption or cessation in ongoing care could therefore have a lasting impact on a child's life and may cause that child serious physical and psychological harm. In ensuring that treatment is not prevented, halted or interrupted for the affected cohort, the Bill has a legitimate purpose of avoiding serious harm to these children, as well as avoiding the significant limitation of the rights of the affected cohort, and overall protecting the best interests of children in this cohort.

Therefore, the objectives of this Bill are legitimate and consistent with the original intentions of the Act and the key principles underpinning it.

In terms of the limitation of the right to equal protection of the law without discrimination, the limitation of the Bill relates to the fact that people who have commenced treatment prior to 23 December 2024, will be treated differently than people who commence treatment after 23 December 2024 (new patients).

Due to the unanticipated issues around implementation of the Act, as set out above, if section 10 and part 4 of the Act were to apply equally to everyone from December 2024, the result may be an unequal outcome. This is because members of the affected cohort without treatment plans in place by 23 December 2024 would be placed at increased risk, as they may be required to cease treatment or have their treatment disrupted. For example, a child may be already undergoing hormone therapy which is a restricted medical treatment, and their clinician would be required by the Act to cease or disrupt treatment. In contrast, and demonstrating the unequal outcome, the treatment approach for new patients would be developed as the variation in sex characteristics is first diagnosed, allowing a treatment plan to be put in place to support restricted medical treatments which are expected to become necessary in the future.

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

Section 10 and part 4 of the Act provide an additional layer of assurance that the rights of prescribed persons, to be free from discrimination in respect of medical treatments they receive, are protected. Section 10 and part 4 of the Act do this by requiring the Board to approve treatment plans before restricted medical treatment can be authorised. The recently discovered challenges faced by health practitioners in the ACT which affect their ability to prepare treatment plans for the number of prescribed persons who have received medical treatment, compromises the Board's timely review of treatment plans, which would undermine the Board's effectiveness in providing the additional assurance, and – as noted above – could lead to delay, interruption or cessation of ongoing treatment which could be harmful to the affected cohort.

Accordingly, delaying the application of section 10 and part 4 for those in the affected cohort, whilst limiting the assurance provided by the Board's approval of treatment plans, will ultimately be effective to prevent the worse outcome of delaying, interrupting or ceasing necessary time-critical treatments.

In relation to the discriminatory effect of the Bill, in that it treats the affected cohort who have received treatment prior to 23 December 2024 differently from other prescribed people, the limitation is directly connected to the purpose of ensuring that the affected cohort continues to receive time-critical and necessary medical care, and to ensure that the Act operates as intended.

By treating the affected cohort differently under the law for a transitional period, the Bill will ensure that they are able to receive similar outcomes to other people receiving treatment; that is, necessary and uninterrupted treatment.

4. Proportionality (s28 (e))

The ACTHD explored numerous options prior to settling on the approach of the Bill as the least restrictive of the rights protected by the Act (including the right to be free from discrimination, and each of the other rights limited and set out below) whilst still allowing access to necessary restricted medical treatments for the affected cohort.

Significant thought has been given to the safeguards which can be put in place and alternative approaches available. These alternative approaches and safeguards are outlined below.

Number of people in affected cohort is small

This Bill will affect a very small number of people. People with variations in sex characteristics are around one to two percent of the population. The affected cohort is a small subset of these, as it is confined to people:

- already receiving a medical treatment related to their variation in sex characteristics,
- who do not have decision-making capacity, and
- the treatment they will need to receive in the transitional period is a restricted medical treatment.

By targeting the Bill as narrowly as possible to the needs of the affected cohort, the Bill also narrowly confines the limitation of the protections offered by the special measures put in place by the Act.

Delayed commencement of section 10 and part 4 is for the shortest possible period of time and does not affect the development of treatment plans.

The twelve-month timeframe for the transitional period was considered the shortest possible timeframe in which the ACT Government can reasonably address the unanticipated implementation issues outlined above.

Given the transitional period is only twelve months, persons undertaking restricted medical treatments on those in the affected cohort during the transitional period will still need to undertake the process of developing a treatment plan to be reviewed and approved by the Board by 23 December 2025.

Accordingly, practitioners will still be required to make treatment plans, however the mandatory requirement for them to be approved before restricted medical treatment can occur will be delayed for the duration of the transitional period. This means that the assessment criteria in sections 13 and 16 of the Act, which help to protect against discriminatory treatment practices, will still be considered during the transitional period as practitioners provide care to the affected cohort.

This will help to ensure that prescribed people are protected from the effects of stigma, even though the explicit legal protection afforded by section 10 and part 4 is delayed for the transitional period. This approach therefore still mitigates, in practice, the adverse outcomes the Act intended to prevent. Accordingly, this approach is the least restrictive of all available options in the current circumstances.

Delayed commencement only applicable to affected cohort

If the transitional period applied to all prescribed persons including new patients, the special measures under the Act would be further delayed for everyone. This would limit the rights of all prescribed under the Act, rather than the defined cohort.

The Bill therefore carefully circumscribes those in the affected cohort to those currently receiving medical treatment, as it is this group whose health and wellbeing is placed most at risk if their treatment were to be halted or disrupted. This allows for the special measures in the Act to apply to all other prescribed persons and confines the limitation on the rights of the affected cohort to the protection provided by the special measures, in the most limited way possible.

In respect of the Bill treating those who have received treatment prior to 23 December 2024 differently from other prescribed persons, this is necessary in order to protect the affected cohort whilst still applying the special measures in the Act to as many people as reasonably possible in the circumstances.

Other administrative safeguards

Additional assurance is also provided by the nature of the treating teams for the affected cohort of children. Most, if not all, of the affected cohort of children are being treated either directly by public health practitioners at CHS, or in accordance with diagnoses and recommendations from clinicians at CHS. CHS will work progressively to develop and submit individual treatment plans for the affected cohort over the course of the transitional period, with those treatment plans to be developed in light of the requirements of sections 13 to 16 of the Act which guard against discriminatory treatment practices. This will help to safeguard the rights of the affected cohort during the transitional period. CHS and ACTHD will work collaboratively to draft General Treatment Plans where appropriate.

Other approaches considered and excluded

In the process of considering and coming to the approach set out in the Bill, a number of alternative approaches were considered to determine the least restricted alternative.

The first alternative approach considered was to legislatively amend the commencement date for section 10 and part 4 of the Act. This solution would have had the benefit of applying to all prescribed persons equally, and therefore may have been less restrictive right to recognition and equality before the law. This approach would have also provided certainty for the affected cohort, and offered the benefits of

clarity and transparency, in that it reflected the issues being experienced by the affected cohort, clinicians and the Board which are driven by issues in relation to implementation. However, as this approach would have applied to new patients as well as the affected cohort, it was considered more restrictive of the rights (including the right to be free from discrimination) of all prescribed people which are protected by the various special measures put in place by the Act. By tailoring the transitional arrangement to the affected cohort, the Bill is less restrictive of the rights of prescribed people as a whole under the Act.

A second alternative considered was to prepare a legislative amendment which only delayed the offence provisions in part 4 of the Act for the relevant period, without amending the application of section 10. This would have had the advantage of retaining the mandatory obligation for oversight of the Board, but without that being supported by criminal offences relating to undertaking restricted medical treatments. This would preserve the special measures which protect the rights of people with a variation in sex characteristics to ensure they are free from discriminatory practices in receiving medical treatment, at least in part.

Whilst this alternative may have been less restrictive of the rights of the affected cohort, it would not have been effective to achieve the legitimate purpose of the Bill. This is because the requirement in section 10 of the Act would still have commenced and would be applicable to those in the affected cohort, meaning that health practitioners would still breach the law if they provided the necessary and time-critical treatment to a person before receiving approval from the Board. This approach would not have achieved the legitimate purpose, as practitioners cannot provide medical treatment in a way which is inconsistent with the law. Doing so would expose those practitioners (being public servants) to breaches of the *Public Sector Management Act 1994,* to issues in relation to uninsured liability, and to regulatory consequences under the *Health Practitioner Regulation National Law (ACT).*

Another approach which was considered was to amend the *Variation in Sex Characteristics (Restricted Medical Treatment) Regulation 2023* (Regulation). Under the Act, the Executive may make a regulation under section 7(1) to exclude or include various conditions as a variation in sex characteristics under the Act. This power was included in the Act to provide for appropriate flexibility and review, given the complex clinical environment that the Act responded to, as well as the nationally and internationally leading nature of the reform.⁵

The Regulation as made in 2023 excludes several conditions. The general rationale for the exclusion of the conditions in the Regulation was based on consideration of a range of information considered to identify variations in sex characteristics that did not need the protections of the approval process in the Act. This information included assessing the frequency with which issues were raised around the outcome of care for people with different variations; the classification of variations in sex characteristics

⁵ Explanatory Statement, Variation in Sex Characteristics Act 2023

in the medical literature; the views of stakeholder organisations; the potential for ambiguity or confusion when determining whether a particular bodily condition was a variation in sex characteristic or not; as well as the overall impact the inclusion or exclusion of the condition would have on the operation of the legislative scheme.

Of the people within the affected cohort, there are a proportion who have one of a limited number of additional conditions, which it may be appropriate and consistent with the legislative intent of the Act to exclude pursuant to section 7(1)(c).

This approach may be considered to be less restrictive of the rights of the affected cohort, as it would only affect the special measures put in place by the Act to protect the rights of prescribed people (including the right to be free from discrimination in receiving medical treatment), in respect of a specified number of appropriate conditions. However, this approach would not achieve the policy intent in full.

The disadvantage of this approach is that it may resolve the inability to legally access medically necessary treatment for only a portion of the affected cohort. A further disadvantage of this approach would be that for the period within which the conditions were excluded, the Board would not be able to consider or approve treatment plans for those conditions – including new patients with the conditions. This means that the protection of the right to be free from discrimination offered by the independent oversight of the Board, would be undermined in respect of the excluded conditions. In contrast, the Bill allows the Board to continue to receive, consider and approve treatment plans for the affected cohort, in preparation for the end of the transitional period. Although it is expected that the Regulation will be regularly updated and amended (including to include and exclude particular conditions) and it is open for the Executive to do so in line with the intended flexibility of the regulatory approach of the Act, the Bill affords a more transparent approach for the affected cohort.

Section 9 - Right to life

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

Under section 9 of the HR Act, everyone has the right to life including the right to not be arbitrarily deprived of life.

Discrimination and prejudice towards people with a variation in sex characteristics are key factors in increasing their risk of mental illness and poor wellbeing outcomes. To address these issues, the Act instituted special measures to ensure protection of people with a variation in sex characteristics from discriminatory practices in the provision of medical treatment, which in turn promotes their right to life.

As with the right to equality and non-discrimination, given the Bill will delay the application of section 10 and part 4 of the Act for the affected cohort, it will also delay application of the special measures put in place by the Act for this group.

2. Legitimate Purpose (s28(b))

As with the right to equality and non-discrimination, the objective sought to be achieved by the Bill is to ensure that the affected cohort continues to receive time critical and necessary medical care.

As with the right to be free from discrimination, given the current challenges faced by health practitioners and the Board to prepare and review treatment plans for the existing cohort of patients – which have only recently become apparent – restricted medical treatments which may be considered to be acceptable by the Board and consistent with the person's wishes could be prevented from occurring. These treatments could be time-critical depending on the person's age, onset of puberty and the person's particular variation in sex characteristics.

Any delay, interruption or cessation in ongoing care could therefore have a lasting impact on a child's life and may cause that child serious physical and psychological harm. This would in turn pose a greater risk to the right to life of the affected cohort, given the affected cohort is already at increased risk of mental illness and poor wellbeing outcomes.

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

Section 10 and part 4 of the Act, which together mandate oversight of the Board for restricted medical treatments, provide an additional layer of assurance that the rights of prescribed persons to be free from discrimination in respect of medical treatments they receive are protected. Given that discrimination is one of the key factors in increasing the risk of mental illness and poor wellbeing outcomes for people with a variation in sex characteristics this also operates to protect the right to life for this group.

Again, the recently discovered challenges faced by health practitioners in the ACT affect their ability to prepare treatment plans for the number of prescribed persons who need them. In turn this compromises the Board's timely review of treatment plans, which subsequently undermines the Board's effectiveness in providing the additional assurance, and - as noted above - could lead to delay, interruption or cessation of ongoing treatment which could be harmful to the affected cohort.

As set out above, this amendment will affect a very small number of people. An example of a person in the affected cohort could be a young child with Turner Syndrome who has been receiving hormone treatment, and for whom disruption of that existing treatment could adversely affect their health.

For the young child in the example, the impact of the unanticipated issues in implementation, which result in a treatment plan being unable to put in place, would be an uncertain treatment future and likely adverse physical and psychological health outcomes. To support an application for a treatment plan for this child would require multiple medical appointments to gather the mandatorily required evidence on

treatment alternatives, decision-making capacity and information provision and support. The child may need to undertake a formal capacity assessment, which would require testing of the child's understanding of a range of complex information about their care. Delaying the mandatory oversight of the Board would give time and be effective to support this process.

4. Proportionality (s28 (e))

The approach taken by the Bill to delay the commencement of section 10 and part 4 of the Act is the least restrictive approach available to the right to life because, out of all other available approaches, it best manages to protect the right to life of both the affected cohort and other prescribed persons.

As with the right to be free from discrimination, the Bill limits the right to life in that it delays the application of the special measures of the Act mandating oversight of the Board of restricted medical treatments, which ensure medical treatment is provided in a non-discriminatory way, and in turn promote the right to life. The Bill has been targeted, scoped and safeguarded in a number of ways to ensure that the limitation of the special measures put in place by the Act is as narrowly confined as possible to achieve the legitimate purpose or ensuring harm is not suffered by the affected cohort by reason of the delay or disruption of their treatment. As set out in some further detail above in respect of the right to be free from discrimination, the ways in which the rights of the affected cohort are safeguarded, and the alternative approaches considered are as follows:

- The Bill will affect only a small cohort of people with a variation in sex characteristics, who do not have decision making capacity, who need restricted medical treatment, and who are already receiving medical treatment in relation to their variation in sex characteristics.
- The delayed commencement of section 10 and part 4 is for the shortest possible period of time and does not affect the processes of the Board in receiving, considering and approving treatment plans for the affected cohort.
- The drafting of the transitional arrangement has been carefully confined to only delay section 10 and part 4 in respect of the affected cohort.
- Assurance is provided by the fact that most, if not all, of the affected cohort are being treated by CHS clinicians who will progressively develop and submit treatment plans in accordance with the protections in sections 13 to 16 of the Act.
- Of the legislative and regulatory options available, the approach taken in the Bill is the least restrictive alternative of the rights of prescribed people, promoted by the special measures put in place under the Act, and will still be effective at ensuring treatment for the affected cohort is not halted or disrupted.

In light of the safeguards and limitations on the Bill, it is unknown whether there would be any difference in treatment outcomes for the affected cohort if they were to have had a treatment plan approved prior to 23 December 2024, and received only restricted medical treatments which were approved in that plan. Accordingly, whilst there is evidence that supports the need for independent oversight as a mechanism to ensure the rights of people with a variation in sex characteristics are protected from discrimination and harm, it is currently unclear whether such oversight would result in different treatment outcomes for the affected cohort.

In contrast, the risks to the affected cohort in having their treatment halted or disrupted are clear. The Bill therefore balances the theoretical risk of harm – which is safeguarded against in various ways described above – against the known risk of actual harm for that same cohort.

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

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

Under section 10(2) of the HR Act, no-one may be subjected to medical or scientific experimentation or treatment without their free consent.

The Act promotes this right by requiring in section 13(1) the Board 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.

Section 16 of the Act then requires the Board may only approve a treatment plan if reasonable steps have been taken in assessing that the prescribed person does not have decision-making capacity. Section 10 and part 4 are then designed to promote this right to be free from medical treatment without consent by providing legal protection to persons with a variation in sex characteristics via mandatory independent oversight of restricted medical treatment. This mandatory oversight ensures that the above considerations in section 13 to 16 of the Act – which give effect to the person's wishes and ensure reasonable steps have been taken to consider the person's capacity to consent– have been taken into consideration.

In delaying the application of section 10 and part 4 of the Act in relation to the affected cohort for twelve months, the Bill limits this right.

2. Legitimate Purpose (s28(b))

As with each of the rights outlined above, the objective sought to be achieved by the Bill is to ensure that the affected cohort continues to receive time critical and necessary medical care.

As with the right to be free from discrimination, given the barriers to preparation and approval of treatment plans by the Board, restricted medical treatments which may be considered acceptable by the Board and consistent with the person's wishes could be prevented from occurring. These treatments could be time-critical depending on the person's age, onset of puberty and the person's particular variation in sex characteristics.

As set out above any delay, interruption or cessation in ongoing care could therefore have a lasting impact on a child's life and may cause that child serious physical and psychological harm. The Bill would allow such medically necessary treatment to occur, and therefore will be effective to address the risks to the affected cohort.

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

The Bill will be effective to allow further time for treatment plans to be put in place to support the continued and future treatment of the affected cohort.

As set out in the overview, the development and approval of treatment plans is an intensive process for the prescribed person and their family. To assess whether the prescribed person is not able to consent to the treatment themselves, and to ensure the prescribed person's views have been adequately taken into account in the development of an individual treatment plan, a sensitive and sometimes lengthy series of conversations with the prescribed person is required, alongside delivery of appropriate psychosocial supports. This process takes time and sensitivity, and if rushed can pose risks to the wellbeing of the prescribed person.

As with the other rights the Bill limits, the limitation on the right not to be subject to treatment without consent relates to the delay of the legal protections afforded by the Board's mandatory oversight of restricted medical treatments, which ensures that section 13 to 16 of the Act – which give effect to the person's wishes and which ensure that the reasonable steps have been taken to assess the individual's capacity to consent – have been taken into consideration.

Delaying the mandatory oversight of the Board for the transitional period will be effective to ensure there is sufficient time to assess capacity of individuals in the affected cohort, and to ensure treatment plans have been developed in accordance with the wishes of each person in the affected cohort.

Accordingly, delaying the application of section 10 and part 4 for those in the affected cohort, whilst limiting the assurance provided by the Board's approval of treatment plans, will ultimately prevent the worse outcome of delaying, interrupting or ceasing

necessary time-critical treatments, and provide adequate time for the wishes of the prescribed person to be appropriately considered.

4. Proportionality (s28 (e))

As with the rights outlined above, which are limited due to the delay of the mandatory oversight of the Board, the Bill limits the right not to be subjected to medical treatment without free consent, in that it delays the legal protections for consent under the Act.

The Bill has been targeted, scoped and safeguarded in a number of ways outlined in respect of the right to be free from discrimination set out above. The particular ways in which the right to consent is safeguarded and/or confined to the purpose are as follows:

- The Bill will affect only a small cohort of people with a variation in sex characteristics who do not have decision making capacity, who need restricted medical treatment, and who are already receiving treatment in relation to their variation in sex characteristics.
- The delayed commencement of section 10 and part 4 is for the shortest possible period and does not affect the processes of the Board in receiving, considering and approving treatment plans for the affected cohort. In particular, where a treatment plan is assessed by the Board it may only be approved if it is consistent with the person's wishes (to the extent the individual can express those wishes) and reasonable steps have been taken to assess whether the individual has capacity (section 16).
- Assurance is provided by the fact that most, if not all, of the affected cohort are being treated by CHS clinicians, who will progressively develop and submit treatment plans, in accordance with the protections in sections 13 to 16 of the Act.

As with the proportionality analysis for the right to life, the Bill balances the known risks to the affected cohort of not being able access medically necessary treatment against the potential (but unknown) difference to treatment outcomes by reason of the oversight of the Board. The Bill therefore balances the theoretical risk of harm – which is safeguarded against in various ways described above – against the known risk of actual harm for that same cohort. Therefore, the Bill is proportionate to the legitimate purpose.

Section 11 - Right to protection of the family and children

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

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.

As noted above, the rights of children are interpreted by reference to the rights contained in the Convention on the Rights of the Child.⁶ This Convention encourages state parties to support families when undertaking their responsibilities toward children.

The Act promotes this aspect of this right in part 3, which creates a system of treatment planning for people with variations in sex characteristics, who will in practice often be children, and promotes the delivery of advice to both the person with a variation and to their family. The Act promotes the right to protection of the family and children with variations in sex characteristics through ensuring:

- Independent oversight of the assessment of a child's capacity to make their own decision (section 16(a)).
- That the child and their family or decision maker are given sufficient information about the implications of the proposed treatment, the likelihood of future treatments, alternative medical and non-medical options, and the likely risks and benefits of deferring or not undertaking the proposed treatment (sections 16(b) and 16(d)).
- That the child is given, or has 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 10 and part 4 are designed to promote the right to protection of children by providing legal protection for children with a variation in sex characteristics via mandatory independent oversight of restricted medical treatment to ensure that the above considerations in section 13 to 16 of the Act – which give effect to the children's wishes and support their families – have been taken into consideration. In delaying the application of section 10 and part 4 of the Act in relation to the affected cohort for 12 months, the Bill limits this right.

2. Legitimate purpose (s28(b))

As with each of the rights outlined above, the objective sought to be achieved by the Bill is to ensure that the affected cohort continues to receive time critical and necessary medical care.

⁶ United Nations Convention on the Rights of the Child, November 20, 1989, <u>https://www.ohchr.org/en</u>.

In respect of the rights of children specifically, in every decision which is made in respect of a child, the best interests of that child must be a primary consideration. The delay, interruption or cessation of treatment for the affected cohort would negatively impact the rights of those children in the affected cohort to access necessary medical care, and to the appropriate protections consistent with the Convention on the Rights of the Child. Fundamentally, it is not in the best interests of the children in the affected cohort to be unable to legally access necessary medical treatment, including restricted medical treatment. In line with this, the legitimate purpose of the Bill is to allow treatments which are in the best interest of children in the affected cohort.

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

The rational connection between the limitation and the purpose is as set out for the limitation of the right to life.

The Bill responds to the need to ensure continued access to medically necessary treatment for the affected cohort, in the best interests of children forming a part of that cohort. Delaying the application of section 10 and part 4 for those in the affected cohort, whilst limiting the assurance provided by the Board's approval of treatment plans and consideration of the best interests of the child, will ultimately prevent the worse outcome of delaying, interrupting or ceasing necessary time-critical treatments.

4. *Proportionality (s28(e))*

As with the rights outlined above, which are limited due to the delay of the mandatory oversight of the Board, the Bill limits the right to the protection of the child in that it delays the legal protections for children under the Act.

The Bill has been targeted, limited and safeguarded in a number of ways outlined in respect of the right to be free from discrimination set out above.

The particular ways in which the right of children to appropriate protection is safeguarded and/or confined to the purpose of the Bill are as follows:

- The Bill will affect only a small cohort of children with a variation in sex characteristics who do not have decision making capacity, who need restricted medical treatment, and who are already receiving treatment in relation to their variation in sex characteristics.
- The delayed commencement of section 10 and part 4 is for the shortest possible period of time and does not affect the processes of the Board in receiving, considering and approving treatment plans for the affected cohort. Where a treatment plan is assessed by the Board it may only be approved if, it is consistent with the persons wishes (to the extent the individual is capable of expressing those wishes) and reasonable steps have been taken to assess whether the individual has capacity, in accordance with section 16 of the Act.

• Assurance is provided by the fact that most, if not all, of the affected cohort are being treated by CHS clinicians, who will progressively develop and submit treatment plans, in accordance with the protections in sections 13 to 16 of the Act.

Section 12 - Right to privacy

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

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

As the right to physical, psychological and bodily integrity is promoted by the Act, the delay of the legal protections for the affected cohort introduced by the Bill will also limit this right in the same way as it limits section 10 of the HR Act set out above.

2. Legitimate purpose (s28(b))

The legitimate purpose of the Bill in limiting the right for privacy is the same as for the right not to be subjected to medical treatment without free consent, set out above.

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

The limitation on the right to privacy is directly connected with the purpose of ensuring the affected cohort continues to receive time-critical and necessary medical care, and to ensure that the Act operates as intended. This is as set out for the right not to be subject to medical treatment without free consent under section 10(2) of the HR Act.

4. Proportionality (s28 (e))

As with the rights outlined above, which are limited due to the delay of the mandatory oversight of the Board, the Bill has been targeted, scoped and safeguarded in the same way as outlined in respect of the right not to be subject to medical treatment without free consent. Further detail in respect of these matters is also set out in respect of the right to be free from discrimination set out above.

VARIATION IN SEX CHARACTERISTICS (RESTRICTED MEDICAL TREATMENT) AMENDMENT BILL 2024

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) AMENDMENT BILL 2024**. 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*.

.....

Tara Cheyne MLA Attorney-General

CLAUSE NOTES

Clause 1 Name of Act

This clause provides that the name of the Act is the Variation in Sex Characteristics (Restricted Medical Treatment) Amendment Act 2024 (the Act).

Clause 2 Commencement

This clause provides for the Act to be commenced immediately following the Act's notification day.

Clause 3 Legislation amended

This clause provides that this Act amends the Variation in Sex Characteristics (Restricted Medical Treatment) Act 2023 (the VSC Act).

Clause 4 New Part 9

This clause inserts a new Part 9 'Transitional'

The Part introduces a new transitional arrangement which applies to prescribed persons who have received medical treatment in relation to their variation in sex characteristics prior to the commencement of section 10 of the VSC Act.

New section 49 defines the commencement day for the transitional arrangement to be the day section 10 of the VSC Act commences (23 December 2024).

New section 50 provides that section 10 and part 4 of the VSC Act will not apply to prescribed persons who have received medical treatment in relation to their variation in sex characteristics prior to the commencement day.

This will permit restricted medical treatment to be provided without an approved treatment plan to a prescribed person who, prior to 23 December 2024, had already received medical treatment in relation to their variation in sex characteristics.

This transitional arrangement will be in place for 12 months from the commencement day, after which section 10 and part 4 will apply in relation to all prescribed persons.

New section 50(3) defines medical treatment for the purpose of the section to include a surgical or medical procedure or treatment (including the prescription or administration of a drug) and makes clear that the medical treatment received prior to the commencement day need not have been restricted medical treatment.

New section 51 provides that Part 9 expires two years after the commencement day defined in new section 49.