



**ACT**  
Government

# PROTECTING THE RIGHTS OF INTERSEX PEOPLE IN MEDICAL SETTINGS

**Listening report on  
submissions received about  
regulatory options**

Chief Minister, Treasury &  
Economic Development  
Directorate

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# EXECUTIVE SUMMARY

The ACT Government is committed to the equality of all Canberrans, and to undertaking law reform to achieve this. Under the Capital of Equality First Action Plan 2019-2021, the government has committed to working with intersex people, human rights experts and healthcare professionals to consider how to best protect the rights of people with variations in sex characteristics within Canberra. This work is being undertaken in recognition of the Darlington Consensus Statement on intersex human rights, and to consider how it impacts the ACT.

This listening report shares key insights from submissions received to an ACT Government regulatory options paper that was released between June 2021 and August 2021. We asked for information and advice from identified stakeholders on various aspects of how the primary approach under consideration, described as a regulatory framework, could be designed to ensure it will achieve the effect desired.

This listening report aims to provide transparency regarding the perspectives and issues received, and one element in a broader engagement process. The regulatory options paper was developed using submissions gathered early in 2021, and feedback through a legal workshop conducted in April 2021.

Through an open submission process, 12 submissions were made by organisations across the health, human rights, intersex and LGBTIQ+ sectors with relevant expertise and experience. One other organisation endorsed a submission by another rather than providing their own.

All submissions agreed that it is desirable to defer a range of medical interventions, leaving future decision-making options for individuals. Points of agreement included:

- > Teams containing diverse professionals and skillsets are best placed to support individuals and their families with medical decision-making.
- > Adopting some form of tiered approach that is responsive to differences in risk and/or urgency of different medical interventions
- > More psychosocial and peer support for individuals and families and research to support evidence-based decision-making.

There were some divergent views, with submissions disagreeing on the following issues:

- > What variations and medical interventions should be included in the scope of the framework. Views diverged on whether the scope includes any variation in sex characteristics, or only people for whom assignment of sex at birth is not possible or straightforward.
- > Which medical interventions could potentially be deferred, and what medical interventions should be exempt from the regulatory framework.
- > How a proposed oversight body would work, including who is represented on it and what powers it should have.
- > While there was support for a tiered approach, submissions presented different views on what should constitute the different tiers.

Submissions also provided perspectives on the principle of personal informed consent for medical interventions and input on how to support minors to make decisions.

The submissions will be used to shape the design of a regulatory framework that could operate in the ACT and that will protect the rights of people with variations in sex characteristics.

The feedback will also support future community engagement on a model for intersex protections when advice on a potential design is expected to be sought by the ACT Government later in 2021.

You can stay up to date with this project, and the work of the Office of LGBTIQ+ Affairs at: [www.act.gov.au/lgbtiq](http://www.act.gov.au/lgbtiq) or by e-mail at [intersex@act.gov.au](mailto:intersex@act.gov.au).

## CONTEXT

In the First Action Plan of the Capital of Equality Strategy, the ACT Government committed to protecting the rights of people with variations in sex characteristics. It said it would work with them, their families, healthcare professionals and human rights organisations to consider the best approach to protect their rights in healthcare settings.

In December 2020 the Office of LGBTIQ+ Affairs circulated a discussion paper to stakeholders seeking initial input into how the government should approach the healthcare and human rights of people with variations in sex characteristics. This resulted in 15 submissions from across intersex, LGBTIQ+, human rights and health professional organisations and individuals. This discussion paper and a listening report is available at [www.act.gov.au/lgbtiq](http://www.act.gov.au/lgbtiq).

Following that consultation and further development of this work, including a legal workshop, the ACT Government circulated a regulatory options paper in June 2021. This described in greater detail the primary approach under consideration, called a regulatory framework. This asked for input on several key design options for such a framework.

This regulatory options paper was circulated to the same stakeholders, as well as additional stakeholders identified during the 2020 consultation. It was also published online and stakeholders were encouraged to forward information about the options paper to interested individuals and organisations.

This report summarises what stakeholders told us in response to the regulatory options paper.

Throughout this report, some technical, biological and medical terms are used, and these are explained in the glossary at the back.

## WHO RESPONDED?

Twelve submissions were received, from across intersex, LGBTIQ+, and health professional organisations and individuals. This included input from the medical professionals outside the ACT that work with some of the rarer and more complex variations in sex characteristics. It also included a video recording of a discussion meeting convened by an intersex community organisation that was submitted as a response to the consultation.

The submissions were:

- > 2 from individuals
- > 10 from organisations or groups

There were:

- > 5 from intersex or LGBTIQ+ organisations
- > 7 from health professionals or organisations, including 2 from organisations for mental health professionals

There were:

- > 2 from ACT organisations and individuals
- > 6 from national organisations or groups
- > 4 from state-based individuals and organisations

One other submission was received, in addition to the twelve, that endorsed the submission of another organisation rather than providing their own response.

In addition to these submissions, staff from Canberra Health Services participated in a workshop that discussed the regulatory options. The Office of LGBTIQ+ Affairs also made a presentation to the ACT Multicultural Advisory Council, and invited comments from this group. Information from both these discussions is also reflected here.

The views and suggestions in this report are generally similar to those from our first phase of consultation, which is what we expected.

## WHAT WE HEARD

### Overview of common ground

Submissions agreed that there were at least some medical interventions which it was desirable to defer, and to leave future decision-making to an individual when they were able to. Submissions also noted that people with variations in sex characteristics represent a very varied group with diverse medical needs that should be considered on an individual basis and supported with individualised care.

Similarly, submissions noted the current absence of appropriate and funded psychosocial and peer support for children with variations in sex characteristics and their families, and the urgent need to provide this. In particular, there was an absence of such support for families when they were making important health decisions. Likewise, many submissions described a need for better resources for children with variations in sex characteristics and their families, and that these are needed for diverse parts of the community.

There was agreement that teams containing diverse professionals and skillsets are best placed to support individuals and their families with medical decision-making. This is discussed further below.

There was broad support for a tiered approach to the issue that recognised different levels of risk for different types of medical interventions, and that created different levels of restriction or oversight in response. This is also discussed further below.

Finally, submissions highlighted that there is a need for better data and research to support evidence-based decision-making for many variations.

### Overview of divergent views

There are several key issues that stakeholders remain divided on. In general, submissions from mental health professional organisations were aligned with those of intersex and LGBTIQ+ community stakeholders, while professionals and organisations from physical health specialities (such as endocrinology or urology) tended to present a divergent view. However, even within these groupings there were some differences.

The key points of division include:

- > The scope, including whether the regulatory framework should apply to all people or only to people with variations in sex characteristics. Further, there were different views on how to define people with variations in sex characteristics.
- > Similarly, there were divergent views about which medical interventions can potentially be deferred, or what medical interventions should be exempt from the regulatory framework.
- > While there was general support for a tiered approach, there were divergent submissions about how to differentiate between tiers, with different views on what constituted higher and lower risk interventions, and how to define urgent, non-urgent and non-medical procedures under a regulatory framework.

These issues and the range of views presented in submissions are discussed in detail below.

Finally, as with the first consultation process, there were differences in opinion about whether there should be a regulatory framework at all. While, as noted, there was general agreement that some medical interventions were appropriately deferred, some stakeholders maintained that a statutory regulatory framework would be an inappropriate vehicle to achieve this. In general, physical health professionals and their organisations did not want a regulatory framework, while other submitters did. Submissions

- > This would interfere with medical decision-making;
- > This would lead to delays in treatment and negative health outcomes as a result of delay;
- > This would create an unsustainable administrative burden on healthcare professionals.

## KEY QUESTIONS

### Age or capacity

The regulatory options paper presented two primary approaches to who should be protected – whether the framework should protect just children (meaning legal minors), or whether it should protect all persons. Stakeholders were asked to provide their views on this and on how this might be defined.

Stakeholders from intersex and LGBTIQ+ organisations noted that historical cases of harmful intervention were predominantly performed on infants and children, and as such, this was the primary group needing protection. These stakeholders also suggested that providing personal informed consent to a proposed medical intervention was one of the reasons that intervention should be allowed (see sections on exemptions below). They reasoned that the ability to provide consent is generally a function of age - as children got older their ability to provide their informed consent increases in most cases. As a result, there may be legal minors who can provide this – submissions referred to Gillick competency as an established legal test. Equally, these stakeholders also noted that there may be legal adults whose capacity to provide consent is impaired (whether temporarily or permanently). These submissions thus noted that the framework needed to be responsive to this range of potential circumstances, including cases where a person, whether a minor or an adult, had a legal capacity that was unclear or questioned. In this sense, these submissions as well as those from mental health professional organisations, preferred using a measure like Gillick competency rather than a specific age to define who should be protected under the framework.

Submissions from physical healthcare professionals did not generally engage with this question on a detailed level, but two of these submissions did discuss the complexity of determining how long to defer a treatment until the individual can be involved. These submissions noted that there are children old enough to have some understanding and to express a desire or wish, but who would likely not be Gillick competent (for example, children who are 8-12 years old). One of these submissions noted that the process of establishing Gillick competency can be onerous to the individual, their family and their medical care providers. It could create an additional burden if it was necessary under the framework.

### Scope

Regarding scope, the regulatory options paper described two primary approaches; whether to apply to medical interventions affecting the sex characteristics of all people (described as a broad approach), or just to people with variations in sex characteristics (a narrow approach). This is a key question that has a significant impact on the design of the regulatory framework.

Two submissions noted that a broad approach was both consistent with a human rights framework that provided universal protection and ensured that the intent of the framework could not easily be circumvented. Most submissions said that a narrow approach was more feasible and had a smaller risk of creating unintended consequences.

Within the narrow approach, stakeholder views differed about how to define variations in sex characteristics, and thus to whom a regulatory framework should apply. In general intersex and LGBTIQ+

stakeholders defined this to mean a person with sex characteristics (including chromosomes, genitals, gonads, and sex hormones) that differ from medical or biological norms for male or female bodies, in addition to a list of specific variations. These groups argued that both a descriptive definition and a list of specific variations would provide better coverage for this group and limit the potential for circumvention than either of these alone. This proposed list included several variations that may not require surgery, or any medical intervention at all, and/or for which sex and gender assignment is as clear as it is for people without any variation in sex characteristics.

Responses from healthcare professionals, specifically those from physical health specialities (surgery, urology, etc), showed quite a different understanding of variations in sex characteristics. No specific definitions were proposed but these submissions demonstrated they generally viewed what should be in the scope of a regulatory framework to mean people whose variations in sex characteristics presented uncertainty in birth sex assignment and future gender, and/or who “identified” as intersex or as having a variation in sex characteristics.

Further, some variations that were specifically named by intersex and LGBTIQ+ organisations to be included were the same as those named by physical health professionals which should be excluded from the scope of the regulatory framework – hypospadias is the primary example of this, but cryptorchidism (undescended testes), Turner’s Syndrome and Klinefelter Syndrome were all explicitly mentioned as potential exclusions in submissions by physical health professionals.

## Exemptions

All submissions demonstrated that any framework needed to provide exemptions to ensure necessary medical intervention was provided. In this, all submissions agreed that a clear exemption for any intervention required to preserve life and for medical emergencies was crucial. Submissions also demonstrated a shared view that an individual’s ability to provide their personal informed consent (as opposed to informed consent provided by a parent or guardian) to any procedure should be exempt. In this, some submissions from intersex and LGBTIQ+ organisations noted that where a minor was Gillick competent, support for decision-making was warranted, while adults with capacity should be wholly exempt.

Beyond this, the issue of exemptions was an area of diverging views. Intersex and LGBTIQ+ organisations argued that medical interventions rationalised through gender stereotypes and normative functioning should not receive an exemption. Hypospadias was one specific example given of this, where surgery is currently routinely performed in early childhood to ensure a boy with hypospadias has ‘appropriate function’ (that he can stand upright to urinate and that he can urinate cleanly). Intersex groups argue that this surgery is not necessary for physical health and thus should be deferred – in the majority of cases there is not an issue with the ability of the body to expel urine or other physical health issues, and that this surgery is performed due to socio-cultural norms about how a boy’s genitals should look and function. Submissions from physical health specialities argued that hypospadias is not a variation that presents any uncertainty in sex assignment and gender identity, and that there is evidence of the benefit of early childhood intervention, and thus surgical repair of hypospadias should be an exemption (or not included in the scope to begin with – see section above).

Many submissions argued that psychosocial rationales and socio-cultural concerns (including the risk of future stigmatisation or harm), gender stereotypes and technical considerations (such as that feminising surgery is easier than masculinising surgery) should not be valid reasons for an exemption from the framework. Submissions from health professionals did not address these issues, though one submission from a health professional did note that they considered it very difficult to separate psychosocial wellbeing from physical health when considering a medical intervention as these are intertwined parts of overall health.

Finally, two submissions from intersex organisations noted that vaginal dilation was a largely reversible intervention that had resulted in a large degree of distress and trauma due to involuntary or coerced dilation. They argued that dilation should be included, despite being reversible, and that it should not be performed on an individual without their consent.

## Administration and oversight

The regulatory options paper asked stakeholders for their views on how the scheme should be administered. It asked whether a new body should be established to provide advice or decision-making or if there are existing structures suitable for this. The regulatory options paper also asked about how an oversight or advisory body should be established, what its role should be, and what would be needed to make it function effectively.

While there was broad support for a regulatory or oversight body there were significant divisions regarding who should be involved, and what powers such a body would have.

In general, intersex and LGBTIQ+ community submissions proposed that such a group should be grounded in a human rights framework and chaired by a person with a legal and human rights background. Submissions from physical health professionals and their organisations suggested an oversight body take the form of an expanded multidisciplinary team (MDT), similar to what is already in use for some cases, but with input from a broader range of specialties, including mental health professionals. One such submission proposed that a medical professional was best placed to chair such a body.

Likewise, there was a split in whether and how decision-making might be handled. Physical health professionals and their organisations viewed an oversight body as a one that might provide evidence-based information and ensure a range of options and viewpoints were heard, but that for children who couldn't provide consent, their parents or guardians would retain the ability to provide consent on their child's behalf.

Intersex and LGBTIQ+ organisation submissions, as well as those from mental health professional organisations, proposed that an oversight body should regulate and oversee supported decision-making within its human rights framework. One of these submissions suggested that this should be in line with the National Decision-Making Principles set out by the Australian Law Reform Commission. However, these submissions also said there may be a few situations in which the oversight body may take on the role of substitute decision-maker, to uphold human rights objectives.

Regarding the composition of any such oversight there were differing views. All submissions described the need for input and support from mental health professionals such as psychologists, counsellors, and social workers. Further, all submissions acknowledged that input from people with lived experience may be valuable to such a body. However, physical health professionals and their organisations raised concerns about exactly how this would operate. These submissions argued that people with some variations (CAH and hypospadias were examples used) don't typically consider themselves to be intersex or associate with intersex community organisations. As such, they suggested that it would be inappropriate for an intersex community representative with a different variation to take part in an oversight body for such cases.

Regarding the weighting of different perspectives on an oversight body, submissions from intersex and LGBTIQ+ organisations generally proposed that a third of the body should be made up of human rights experts, a third from healthcare professionals (including a mental health professional) and a third from people with lived experiences of variation in sex characteristics (including a parent of a person with a variation). Submissions from health professionals and organisations did not provide this level of detail, but their submissions typically described a representative, indicating that they viewed that a single person with relevant lived experience would be suitable.

Finally, all submissions agreed that if there was to be an oversight body, it must not create any additional stress or burden to access for families, and its administration must be kept to the minimum needed to fulfill its function. This included it being free for all to access, that those with limited legal literacy or from diverse backgrounds were adequately supported in accessing it, and that it must operate within reasonable timeframes.

## Tiered approach

Submitters agreed that if there was to be a regulatory framework, it should be responsive to the different levels of urgency or risk of different medical interventions. In the regulatory options paper, such a system



was described as a tiered approach. However, the support of intersex and LGBTIQ+ organisations for a tiered approach was contingent on how these tiers were constituted. Some submissions queried how a tiered approach would operate in practice.

One submission from an intersex and LGBTIQ+ organisation proposed that tiers should be based on a matrix of capacity and risk, where risk was defined by how invasive and irreversible an intervention was. In the examples provided, 'normalising genital surgeries' (including procedures such as gonadectomies, clitorrectomy, and hypospadias repair, among others) were considered high risk, while hormone/puberty blocking medication was low risk. Another submission from an intersex organisation noted the difficulty in determining risk, noting that community understandings and clinical understandings of these concepts in this context were significantly different. Instead, this submission proposed that tiers should be based on the minimum type of consent required, where personal consent is required for more invasive and/or less urgent procedures, while consent of a parent or guardian would be appropriate for less invasive and/or more urgent procedures. Under both these proposals, for procedures where personal consent was needed, such an intervention would be prohibited until such time that this could be provided via an appropriate supported decision-making process (that reflected the capacity of a child). For procedures where parental consent was appropriate, both proposals noted that the oversight body could be involved in establishing suitable decision-making processes and that the will and preferences of the child should be considered to the extent they can express them.

No other submissions provided this level of detail about the structure of a tiered approach. However, one submission from a mental health professional organisation noted that, where a minor was not Gillick competent, a process of expert advice and oversight was warranted. One submission from a physical health professional organisation noted that tiers of urgent, non-urgent and non-medical interventions would be useful but did not provide input on how to constitute each of these categories.

## OTHER ISSUES RAISED

Submissions from physical health professionals and their organisations suggested that male circumcision should be included as regulated procedures if variations such as hypospadias were included. The reasons presented for this ranged from the human rights inconsistency of excluding circumcision, to the rejection of circumcision because it is a cultural practice with no medically necessary basis.

Submissions agreed that resourced peer support would be welcome and helpful to the functioning of any regulatory scheme. Submissions from physical health professionals and their organisations noted that while referrals should always be made to peer support, engaging with peer support should not be mandatory for individuals or their families.

Lastly, while there was a general agreement within submissions from physical health professionals, there were also diverse views present within the medical community. As noted, mental health professional organisations tended to have a different view from physical health professionals. One anonymous submission was received from an ACT health professional who expressed a view opposed to early medical interventions and who did not want to name themselves for fear of professional repercussions.

## CONCLUSION

Submitters engaged carefully and thoughtfully with the range of questions in the Options Paper. The Office of LGBTIQ+ Affairs is extremely grateful to individuals and organisations for their commitment to address this issue of importance to Canberrans with variations in sex characteristics and to the broader community.

The Office of LGBTIQ+ Affairs will consider all feedback. We will work to design a framework for protecting people with variations in sex characteristics that considers:

- > The concerns and questions raised by submitters;

- > Examples provided by submitters of how specific variations, medical treatments or other issues would be affected by a regulatory framework; and
- > The design and implementation of other relevant regulatory regimes in other jurisdictions.

The next stage of this project will involve providing advice to government. If the government decides to introduce new legislation, draft legislation will be subject to public comment. Stakeholders who made submissions in response to the Discussion Paper and Options Paper will be contacted again when the project reaches this stage.

## GLOSSARY OF KEY TERMS

Parts of this glossary have been extracted from the Australian Senate Community Affairs Reference Committee's inquiry into the forced sterilisation of intersex people in Australia in 2013. We acknowledge that the language used in this glossary is potentially outdated. As such, we have made minor adjustments to update dated language.

**Chromosomes** are found in each cell in the body. Each human cell normally contains 46 total chromosomes – organised in two sets of 23 chromosomes – that come in two types: sex chromosomes and autosomal chromosomes. Each cell in the human body contains these chromosomes which contain genetic material (genes) that make up an individual's DNA (deoxyribonucleic acid). Sex chromosomes determine gender. In the final of the 23 sets of chromosomes, females have two X chromosomes, while males have an X and a Y chromosome; in some intersex people, there are variations in the configuration of the 23rd chromosome set. Phenotypes are produced by multiple chromosomes acting together.

**Clitoroplasty/clitoridectomy** is the surgical excision of the clitoris. Until the 1960s clitoridectomy was the principal surgical procedure used to manage enlargement of the clitoris in intersex. Clitoroplasty is a surgical procedure to alter the physiology of the clitoris and includes procedures in which part of the erectile tissue of the clitoris is removed (clitoral reduction) or relocated (clitoral recession) to reduce the apparent size of the clitoris.

**Congenital adrenal hyperplasia (CAH)** refers to a group of genetic disorders that affect the adrenal glands, a pair of walnut-sized organs above the kidneys. The adrenal glands produce important hormones, including: Cortisol, which regulates the body's response to illness or stress.

**Cryptorchidism** refers to the condition in which one or both testes haven't descended into the scrotum and are retained within the abdomen or inguinal canal.

**Endocrinology** a medical specialisation dealing with the body's production, use and response to hormones. Gonads are reproductive glands; the term can refer to either testicles or ovaries.

**Gonads** in fetuses develop into either testes or ovaries depending on the chromosomal constitution of the foetus. In some intersex people, gonads do not differentiate fully into one type or the other.

**Gonadectomy** - A gonadectomy is the removal of an ovary or testis. In some intersex cases, gonadectomy is undertaken if the testes are inconsistent with the sex assigned at birth. In some complete androgen insensitivity syndrome (CAIS) individuals the testes are intra-abdominal or contained in inguinal hernia (a protrusion of the abdominal cavity).

**Hypospadias** is a development disorder affecting the urethra. In males, it is a developmental anomaly in which the urethra opens on the underside of the penis or on the perineum. In females hypospadias is a developmental anomaly in which the urethra opens into the vagina.

**Intersex** refers to people who have **variations in sex characteristics** relating to chromosomes, genitals, gonads, hormones and other reproductive anatomy, and secondary features that emerge from puberty. As such, intersex people have innate sex characteristics that do not align with medical and social norms for female and male bodies. Intersex people are at risk of experiencing stigma, discrimination, psychological and physical harm.

**Klinefelter syndrome**, a genetic condition that affects males, results when the individual is born with an extra copy of the X chromosome. This can affect testicular growth and testosterone production, which may cause of a range of other developmental variations, such as delayed or incomplete puberty.

**Personal informed consent** is a term used to mean to the informed consent of the individual on whom a medical intervention will be performed. This term is used to distinguish this from the informed consent of a representative (such as a parent or guardian) on behalf of the individual on whom a medical intervention will be performed.

**Puberty blockers** are drugs used that block hormones, such as testosterone, and oestrogen, that lead to puberty in the body. Menstrual periods, breast growth, voice deepening and facial hair growth can be prevented through puberty blockers.

**Turner syndrome**, a condition that affects only females, results when one of the X chromosomes (sex chromosomes) is missing or partially missing. This may cause a range of medical and developmental abnormalities, such as failure of the ovaries to develop, heart defects and short height.

**Urology** is the branch of medicine that focuses on the surgical and medical diseases of male and female urinary-tract system and the male reproductive organs.

**Vaginal dilation** is the use of a medical device to keep open or stretch the vaginal canal.

**Variation in sex characteristics** sometimes referred to as **intersex**, is used to describe physical sex development which differs from what is typically 'male' or 'female'. These variations are congenital and may be chromosomal, gonadal, anatomical, or hormonal.



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