



# Draft Legislation To Protect The Rights Of People With Variations In Sex Characteristics In Medical Settings

Listening report on submissions  
received

Chief Minister, Treasury and  
Economic Development  
Directorate

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## Executive Summary

The ACT Government is committed to upholding the human rights of people with variation in sex characteristics. Under the [Capital of Equality Second Action Plan 2022-2023](#), the government has committed to progressing legislative reform and service improvements to achieve this. This work is being undertaken in recognition of the Darlington Consensus Statement, and to consider how it impacts the ACT. As part of the development of this new legislation, the ACT Government undertook a consultation process on a draft Bill, seeking public comment from the end of May 2022 to July 2022. We asked for information and advice from stakeholders about how various aspects of the legislation should operate.

This report provides transparency regarding the range of perspectives and issues received. The draft legislation that was the subject of this consultation was developed using submissions gathered in response to a previous Discussion Paper in 2020, an Options Paper in 2021 and a legal workshop in April 2021.

Through a public submissions process, a total of 73 written submissions were received. The project team held an additional 10 meetings with external stakeholders and four workshops with key stakeholder groups about specific aspects of the draft legislation.

The feedback received was diverse, covering both common views and divergent views including perspectives to broaden the bill and provide stronger protections and, perspectives that oppose the legislation altogether.

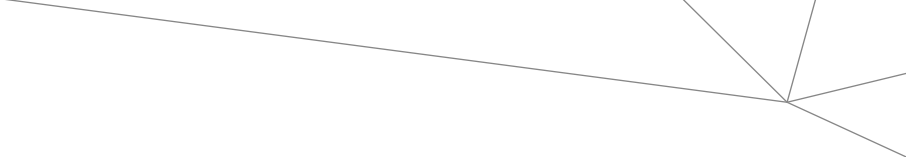
Common views between stakeholders included:

- Recognition there are at least some medical interventions that are best deferred.
- People with variations in sex characteristics represent a diverse group with significant diversity in healthcare needs, and any approach to this issue must be sensitive to the circumstances of individuals.
- Strong support for increased psychosocial and peer support for individuals and the families.

Divergent views were heard from, intersex and LGBTIQ+ organisations and mental health professional organisations, health professionals and their organisations, and parents of people with variations in sex characteristics.

The primary areas of divergence in opinion between stakeholder groups include:

- Intersex and LGBTIQ+ organisations and mental health professional organisations prefer a legislated restriction on medical interventions.
- Health professionals and their organisations and, some parents rejected the need for the legislation, and challenged the scope of the legislation.
- There was significant feedback on a list of proposed variations in sex characteristics that was included in the consultation. These included divergent views, with some stakeholders, especially medical stakeholders, and parents, arguing for the removal of many items from the list, and intersex organisations arguing to expand the list.
- The proposed new statutory committee that would oversee restricted medical interventions, including who is represented on the committee, and the extent of the powers it should have. Medical professionals generally argued that a version of the multi-disciplinary teams already in use would be a better alternative to a new statutory



committee. In contrast, intersex and LGBTIQ+ stakeholders viewed it as important to create an independent committee with decision making powers in some circumstances. They said it should include representation from the intersex community and human rights experts.

These key design features of the legislation remain contentious. The Office of LGBTIQ+ Affairs is continuing to consider all input received during the consultation phase to refine and improve the draft legislation. The ACT Government is anticipating deciding on a pathway forward in the later part of 2022.

You can stay up to date with this work at: [act.gov.au/lgbtiq](https://act.gov.au/lgbtiq) or by email at [intersex@act.gov.au](mailto:intersex@act.gov.au).

## Context

The ACT Government is reforming how care and support is provided to people who have variations in sex characteristics. The reform is being led by the ACT's Chief Minister, Treasury and Economic Development (CMTEDD) with the ACT Health Directorate (ACTHD) providing input on the reforms. CMTEDD has been working closely with stakeholders from across the ACT Government, intersex communities and health professionals since the Government committed to these reforms in 2019.

The Government has held multiple rounds of consultations with a range of stakeholders. In 2020 a consultation with key stakeholders was held about a Discussion Paper seeking input on how to approach the healthcare and human rights of people with variations in sex characteristics. An Options Paper outlining the primary approach under consideration and asking for feedback on several policy issues was released for public comment in 2021. A legal workshop with key experts was also held in April 2021.

Papers and listening reports from all previous consultations and listening reports are available at [act.gov.au/lgbtiq](https://act.gov.au/lgbtiq).

This report is a summary of the consultations feedback received in 2022 on the draft Bill, titled the 'Variation in Sex Characteristics (Restricted Medical Treatment) Bill 2022'. The draft Bill was published online and was also circulated to over 50 stakeholders who were identified during the previous stages of this work. Stakeholders were also encouraged to forward information about the draft Bill to other interested individuals and organisations. You can read a copy of the draft Bill and the consultation materials at [act.gov.au/lgbtiq](https://act.gov.au/lgbtiq).

This report is intended to provide transparency regarding the range of perspectives and issues heard. It is framed around seven questions that stakeholders were asked to respond to, as well as any additional issues that submissions raised. Not all submissions addressed all questions with some choosing to focus only on a few questions or aspects of the legislation about which they had experience or expertise.

Throughout this report, some technical, biological, and medical terms are used, these terms are explained in the glossary in the report's appendix.

## Who Responded?

Consultation on the draft Bill was open from 27 May to 8 July 2022. In response to this, 73 written submissions were received from health professionals, intersex and LGBTIQ+ organisations, parents of potentially affected people, and legal and human rights organisations.

Alongside written submissions, four targeted workshops with key stakeholder groups were held with:

- Health professionals working within Canberra Health Services.
- Health professionals from relevant national medical Colleges and professional bodies.
- Legal and human rights professionals.
- Intersex community members.

An additional 10 external stakeholder meetings were held with stakeholders who had been identified for targeted engagement, or with those who requested meetings. Submitters and workshop participants represented a range of stakeholder types and were from both within the ACT and across Australia and internationally. Information about these is reflected in figure 1.1 and figure 1.2.:

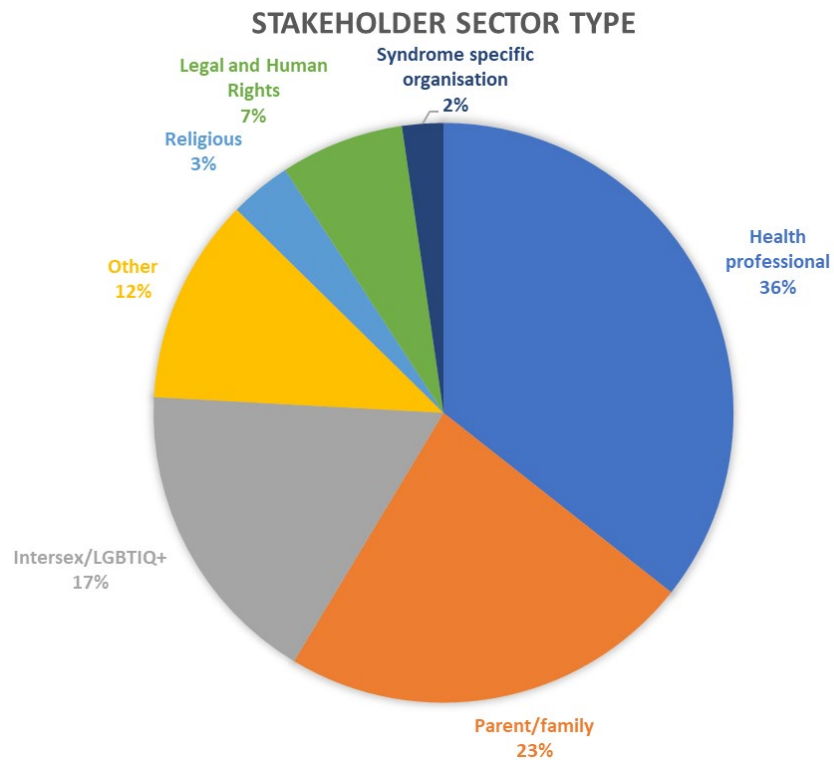


Figure 1.1: Stakeholders by sector type

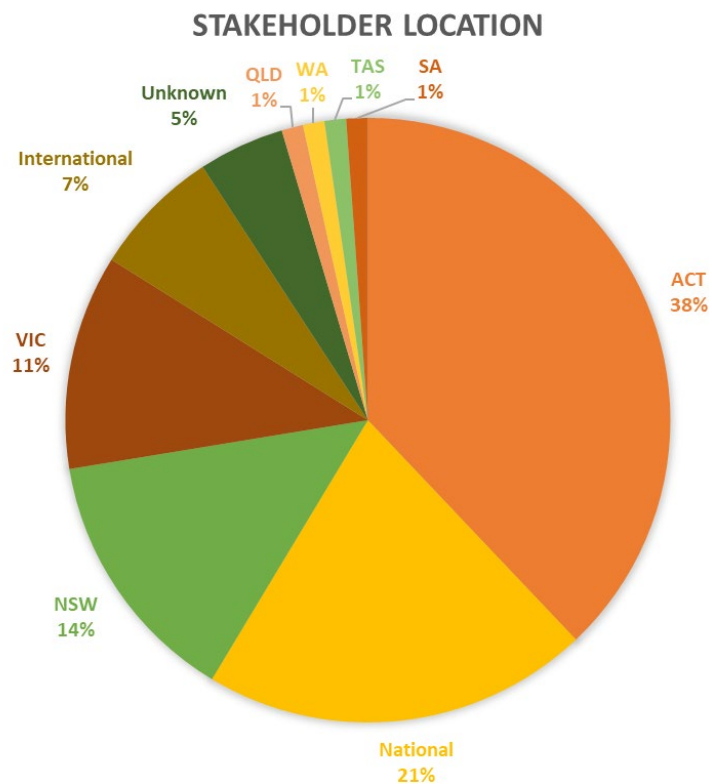


Figure 1.2: Stakeholders by location, including national organisations

# What We Heard

## Principles

### **Will the general principles listed in section 10 of the draft Bill guide to committee to good decisions and care outcomes?**

Most stakeholders who provided detailed responses to this question, offered general support for the principles in the Bill. Most responses recommended making further changes to the current list of principles and adding additional commentary. Other comments that were made sought to clarify, change or add to the existing principles. This included the following:

- Most comments related to reordering the principles listed in the section to reflect the hierarchy of concepts as well as grouping principles thematically. For example, it was suggested that principle (e) (about the considerations of the views and wishes of a protected person) should be the first one given it is being listed as ‘the most important consideration’ in the Bill. Other submitters considered that there should not be more weight given to some over others.
- Rephrasing principle (b) to reflect possible stigma and discrimination rather than harm, given that some variations in sex characteristics are known to harm health if not treated.
- It was suggested that principle (c) be expanded by adding additional points or clarification to the listed factors that should not influence decisions about undertaking restricted medical treatment, including:
  - the feelings, comfort, or emotional needs of the parent(s) or caregiver(s).
  - the possibility a person may experience psychological distress, poor self-image, gender dysphoria, or ‘confusion’ in the development of their sexual orientation or gender identity.
  - reducing the risk of gender dysphoria, and considerations relating to potential marital or other relationships prospects.
  - reduce the risk of gender dysphoria, where this is not raised by the individual.
- Some medical professional stakeholders had a contrary view regarding principle (c), arguing that psychosocial factors or ‘social integration’ should be valid reasons to undertake medical interventions without personal consent.
- Diverse views were expressed about the use of the concept of “function” in principle (c). There was broad support for limiting the use of medical intervention for primarily aesthetic reasons, but stakeholders were divided about medical interventions for function. Some medical professionals noted that function was a key consideration for some surgeries and questioned how to define what functional factors were appropriate to be regulated.
- Strengthening principles (e) and (f) by adding a phrase ‘freely-expressed or given’.
- Adding clarifications in the principle (h) to describe what this support looks like.

Other stakeholders recommended adding additional principles. These included the following:

- To add ‘the right to access non-discriminatory healthcare’ to principle (a).
- To add ‘evidence-based healthcare’ as another principle.
- To add references to the United Nations Convention on the Rights of the Child.

- Adding a principle that expresses the human right of people with variations of sex characteristics to health, without discrimination.

Some health professionals recommended adding a principle about the centrality of child/family care. Some health professionals also argued that their work on children's health is appropriately based on social norms, while other health professionals presented an objection on the opposite grounds: they rejected the argument that intersex healthcare is influenced by social expectations about bodies.

Multiple submissions from human rights bodies and intersex advocates reflected that, while positively worded, some text in the Bill reflects an underlying assumption that a deviation from a supposed social or medical norm will cause harm to a person growing up. They argued there is little or no evidence to demonstrate this. They argued that permitting medical interventions on these grounds perpetuates harmful assumptions about how bodies are 'supposed' to look. They argued that many such norms are rooted in gender stereotypes (for example, that for boys to be boys they need to urinate standing; or that girls will be heterosexual and will need a vagina for future penetrative intercourse). It was argued that such norms are socially imposed rather than vital functions. Comments were made that medical decisions are being made on the assumption that every person will have surgery either now or later, not considering that an individual may not want to have it at all. Examples included surgical reduction of an enlarged clitoris or vaginoplasty. Such stakeholders argued that the principles need to embed respect for individual self-determination.

One stakeholder reflected that there is little recognition of the fact that stigma can come from within families; and that there are unsubstantiated assumptions that medical procedures can improve relationships between parents and children.

It was argued that section 10 does not indicate who must consider these principles, and how or when, if this section applied only to 'undertaking restricted medical treatment on a person'. It was also noted that the Bill does not provide the committee with guidance as to what weight it should give each principle, or what to do if the results of applying different principles conflict with each other.

Concerns were expressed that the Bill does not clearly identify how relevant human rights under the *Human Rights Act 2004* (ACT) interact with the general principles in section 10.

## Scope

### **Are the definitions used for 'sex characteristics' and 'variation in sex characteristics' suitable? Does the list supplied capture and correctly name all variations?**

Divergent views expressed on these questions included the inclusion of specific variations and whether there needs to be an open-ended definition, or a specific list provided in the Bill. The divergence in views arose from whether 'deviating from the norm' brings stigmatisation or not.

### **The following comments were received in relation to the definition proposed for 'sex characteristics' and 'variation in sex characteristics':**

- Intersex advocates argued that 'variation in sex characteristics' as a term is not defined in the draft legislation but that it should be, and that the definition of 'a protected person' relies on capacity for decision-making and on having a trait that is not defined in legislation. Recommendations were made to include a definition for 'variation in sex characteristics'; and to distinguish between protected persons and persons with variation in sex characteristics. They argued that the definition should include reference to 'traits known using the terms intersex, disorders of sex development, disorders of sexual



differentiation, differences of sex development, and including traits currently or historically known using such terms’.

- Several others expressed concern that the definition needs to be open to the potential identification or renaming of variations in the future, and that a fixed list may not readily support this.
- Many submissions recommended adding the word ‘innate’ to the definition of a ‘variation in sex characteristics’. Some expressed concerns that the terminology currently used would include both innate and acquired variations, and that this was not the intention.
- Some commented about the need to remove the word ‘chromosomes’ from the definition of ‘sex characteristics’.
- One submission reflected that the definition is in line with the definition used by the United Nations.
- Some argued about the need to rephrase the definition to exclude organs and tissues not related to reproduction. For example: “genital anatomy, gonads, and other organs or tissues related to reproduction, sex development, and/or sex difference”.
- One stakeholder reflected that there are common assumptions that women want fertility, regardless of whether it is so.
- It was also noted that there needs to be consistency of terminology used such as “people with variations in sex characteristics”, “protected persons”, and “child/children”.

### **Feedback on having a list of variations attached to the legislation varied:**

- Intersex advocates and human rights advocates favoured the inclusion of a legislative umbrella definition of ‘variations in sex characteristics’ that can be expanded via an enumeration of specific traits via regulation. It has been argued that there is a need to ensure the law is able to encompass individuals who should come within the protected person category but who may be excluded as their particular diagnosis either has not yet been settled or their bodily configuration, while clearly variant, does not match the criteria of any existent diagnosis.
- Medical professionals were mostly not in favour of this approach, with some arguing that it is better to define the term ‘people with variations in sex characteristics’ in the legislation with a non-exhaustive list of variations.
- Some medical professionals argued that there needs to be more up-to-date evidence on the current practices in healthcare provided. Also, it was argued that there are variations where delaying treatment will cause harm, and that having them included in the legislation would create unnecessary administrative burden.
- Several submissions from medical professionals also recommended not to conflate acquired and congenital variations within the list.
- Medical professionals also argued that the list of variations mixed terms for diagnoses, descriptions, diseases, and syndromes in ways that made it confusing and unworkable.
- In general, health professionals also stated that the list should only include diagnoses where individuals ‘identified’ as intersex.
- A medical professional commented that the Bill may have unintended consequences on people’s decision to terminate pregnancy should a variation in sex characteristics be identified prenatally.

- In their submissions, multiple parents expressed concerns about the list of conditions, concerned that it was an impediment to parental rights to make decisions about their children.

### **Feedback on the inclusion or exclusion of specific diagnoses was as follows:**

- Intersex advocates recommended addition of the diagnosis hyperandrogenism.
- Multiple submissions from parents/legal guardians and medical professionals recommend removing Turner syndrome from the list. They argued that women and girls with Turner syndrome do not identify as intersex and that an early treatment without a legislative oversight will result in better health outcomes (such as early management of menopause).
- Submissions from healthcare professionals also recommend removing epispadias and bladder exstrophy from the provided list.
- Opinions on the inclusion of hypospadias varied. Parents of boys with hypospadias and medical professionals recommended removing it from the list while human rights organisations and intersex advocates recommended it remain.
- Arguments for the removal of hypospadias from the list (as recommended by healthcare professionals) included the following:
  - There are health benefits associated with early surgery as well as surgery being less complicated when done in childhood.
  - Inclusion in the list will result in greater administrative burden for parents and doctors without any difference in outcome, given the evidence base to support early intervention.
  - It is not a variation in sex characteristics as there is no uncertainty in the sex and gender of the child.
- Arguments supporting the inclusion of hypospadias (as recommended by intersex and human rights advocates) included the following:
  - It is an innate variation in sex characteristics.
  - A human rights organisation argued that while hypospadias, congenital adrenal hyperplasia (CAH) and Klinefelter's syndrome sometimes are erroneously not considered as variations in sex characteristics, people may be subjected to discrimination on these grounds. Being excluded from the list removes a potential remedy for such discrimination.
  - Exclusion of conditions such as hypospadias signals that people with this variation do not deserve the protections and services created by the Bill.
  - Hypospadias repair can result in significant complications and negative outcomes, and as such it needs oversight.
- Submissions from medical professional and parents included arguments for removing the following diagnoses from the list: Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome, Klinefelter's Syndrome, Frasier syndrome with the exception of Denys-Drash, WAGR, DAX1 and SF1 mutations (see Wilms Tumor Suppressor Gene Mutations in glossary), people with complete lack of responsiveness to androgens, people with late onset CAH who overlap with women with polycystic ovarian syndrome (PCOS). It was argued that people with no functioning gonads need timely induction of puberty.
- Other submissions recommended adding several more variations to the list such as cloacal exstrophy, congenital chordee, cryptorchidism, Mullerian Duct Anomalies, and PCOS.

- Divergent views were expressed about the exclusion of male circumcision from the scope.
  - Medical professionals argued that male circumcision needs to be added to the list of regulated medical interventions, as it is inconsistent to regulate all other surgeries except this one, and that there are instances where tissue removed in circumcision would limit future choice for reparative surgery.
  - Some human rights and intersex advocates argued that male circumcision should not be excluded, as circumcision reduces future treatment options for the individual.
  - Representatives from religious groups, including from culturally and linguistically diverse communities, reflected that the practice is important for religious and cultural reasons and should not be prohibited. However, they understood that there can be health implications related to circumcision and considered that, where there are medical reasons to delay circumcision, it would be appropriate and religiously acceptable to defer circumcision.

## Definition of restricted medical treatment

**Are there medical or other treatments that might inadvertently be captured as a restricted medical treatment that we would not want to affect with this Bill? If there are, what are they and why do you think they would they be captured? Will the definition fail to capture any treatments that should be addressed?**

It was strongly suggested that guidelines for medical professionals should be developed and published to assist with interpretation of the legislation and proposed regulation.

Some stakeholders recommended removing section 7(b) from the definition of 'restricted medical treatment' and relocating it to a separate section that describes circumstances in which what would otherwise be restricted medical treatment is permitted.

Additional commentary was provided on the exclusion of circumcision from the scope of the legislation.

It was recommended to provide definitions of medical treatment and of 'deferred wherever possible'.

Medical professionals provided the following comments:

- There is a risk that these treatment plans can become as complicated as National Disability Insurance Scheme (NDIS) applications, which are extremely difficult for many families to navigate.
- Concerns were expressed about the exclusion of parents from the legislation.
- Concerns were expressed about potential timing and delays due to the need to engage with the committee.
- Some requested more clarity on the definition of a reversible procedure and differences between definitions of emergency vs life-saving vs urgent treatments.
- Concerns were expressed about the offence for removing a protected person from the ACT because cross-border care between the ACT and surrounding NSW is common, residency might be difficult to determine or where there is a power of attorney.

Intersex and human rights advocates noted the following:

- There is a need to make definitions consistent across legislation.
- Including the phrase 'diagnosed or not' in the Bill does not work with the list of variations provided, noting that if someone is not diagnosed but the treatment has been provided for other reasons, medical practitioners may not be aware of this Bill.
- It was recommended to remove the distinction between temporary and permanent procedures or make all temporary procedures regulated.
- Concerns were expressed that the exception applying to the prevention of suffering or significant pain or distress can be used by medical professionals or parents to anticipate future stigmatisation without any evidence it will occur. They argued that restricted medical treatments were not an appropriate response to these issues and recommended that the term 'distress' be removed as a ground for exemption.
- It was recommended that reporting requirements be added for procedures that occur under an exemption.

## Committee Structure

**What kinds of experience, skills and expertise do you think a committee needs, and are these the appropriate categories of member to achieve this?**

**Feedback on the skills and expertise of the committee members included the following:**

- Multiple stakeholders recommended including a definition of minimum expertise or qualification requirements.
- There was support for a person with lived experience being on the committee, with medical professionals tempering their support by arguing that this must include representation across diagnoses and conditions, not only those who identify as intersex. Some argued that a person with lived experience should also be required to have additional expertise, for example in community service delivery.
- Recommendations were made for other additional skills or perspectives to be represented. This included (not in any specific order) a social worker who is a member of the Australian Association of Social Workers, a human rights expert, an expert in child development, an expert in disability rights.
- Other representational suggestions included an Aboriginal and Torres Strait Islander person, parental groups, and a faith leader.
- Recommendations were made to include medical expertise in specific areas such as paediatric endocrinology, paediatric surgery, paediatric urology and child psychiatry. It was argued that medical specialisation is essential on the committee, so it is not moved from the medical to the legal realm.

## Other comments pertained to governance issues. These included:

- Comments made in relation to the size of the ACT and availability of experts. For example, if there is only one practicing paediatric surgeon, this could create governance issues if the same person is treating a patient and sitting on a decision-making committee.
- Multiple stakeholders commented on the need to set out a clear process of appointment, indicate a term of appointment in the legislation, possible term limits for reappointment, and provisions for rotation.
- Multiple stakeholders argued that clear obligations need to be placed on committee members such as a duty to act impartially, fairly and declare any actual or perceived conflicts of interests.
- It was argued that the Bill needs to establish a clear framework for decision-making by the committee.
- There were some comments on the role of the president, including several being supportive that the president be excluded from initial committee considerations, to enable them to independently review decisions if required.
- Medical professionals noted it was important to reflect that one person may sit on a similar committee in other jurisdictions, with some recommending utilising an existing differences in sex development multi-disciplinary team (DSD MDT) for NSW/ACT which is made up of medical specialists, geneticists and psychologists.
- Recommendations were made to ensure that any process to review a decision of the committee be structured with the same rigour, consideration of human rights and expertise as was the original decision-making process.
- Some human rights experts argued that the committee needed to have the power to appoint independent advocates for the protected person.
- Some argued that ACT Civil and Administrative Tribunal (ACAT) could not have a twin role in the legislation, as both a party that could make a care plan application and as the source of review.
- The committee should undergo periodic review.
- Several parents in their submissions argued against the creation of the committee, expressing concerns that it would impede their ability to make decisions for their child and that they didn't want others to make these important decisions for them.
- Some submissions from healthcare professionals suggested retaining an informal mediation process between parents and clinicians.
- Health professionals argued that existing DSD MDTs should not be replaced by this proposal.

## General treatment plans

### **Will the process for creating a general treatment plan, outlined in sections 15-19, support appropriate information gathering, consultation, and decisions for establishing a general treatment plan?**

Several submissions expressed support for the treatment plans to be done in alignment with the principles in division 3 of the Bill. Others, especially from health professionals, commented on the need to ensure that any medical treatment plan or the undertaking of restricted medical treatment reflects evidence-based healthcare.

Concerns were expressed that there is no process outlined for improving a general treatment plan over time.

Also, it was noted that the Bill does not provide for clinical scenarios where there are already published high-quality, peer-reviewed clinical practice guidelines.

One stakeholder noted that data regarding proposed general treatment plans should be available to allow public scrutiny and that expert intersex community organisations should be given an opportunity to comment on proposed general treatment plans.

## Individual treatment plans

### **What kind of information should be required and who should be consulted to ensure that a committee can make a well-informed decision for an individual treatment plan?**

Human rights and intersex advocates recommended ensuring there is no need to provide evidence at the initiation of an application for an individual treatment plan but provide these details when the committee meets. It was recommended that the process should be a simple, straightforward, accessible, and inquisitorial process rather than adversarial. Multiple submissions noted that an individual who is being offered medical treatment needs to be involved and fully consulted when developing their individual medical treatment plan.

Submissions from medical professionals noted the following:

- To ensure that there is no need to provide literature review or research papers.
- The number/volume of treatment plans clinicians are managing, as well as the time involved and their complexity, will limit their ability to spend significant time developing plans.
- Information that stakeholders suggested should be included in individual plans included:
  - Sign-off from clinicians to confirm they have gained advice from a DSD MDT on treatment plan.
  - Information about the benefits and risks of treatments (including the benefits and risks of not treating all together).
  - Clear evidence of engagement and support being offered to the person in question.
  - Evidence of consent (or assent) and sufficient engagement with the patient, family and experts.

It was suggested that the ACT Government should establish a fund to assist parents and families to make applications for individual treatment plans.

Several stakeholders noted that the legislation needs a mechanism to end or amend individual treatment plans.

Comments in this section also referred back to the skills and expertise of the committee outlined in the responses on committee structure, above.

Privacy concerns were expressed about the ACT's size as a jurisdiction. Concerns were raised that medical information about the families could become known to non-medical professionals.

## **Informed consent requirements**

### **In your opinion, does section 12 adequately describe informed consent and what is required for it, in the context of a person with variations in sex characteristics consenting to a restricted medical treatment?**

Stakeholders who commented on this expressed support for this section and offered additional comments for improvement.

Submissions from human rights bodies argued for a greater separation between capacity and decision-making rights. It was noted that principles of capacity can work regardless of ability. It was noted that there needs to be more discussion and work done to maximise the ability of children to participate in decision-making. Similarly, one submission argued that the “focus needs to be on enabling the optimal decision-making environment and potential to avoid known risks of making the decision for the person, rather than hypothetical risk of decision regret, which is also a risk of the decision being made for the person.”

In relation to the section on the provision of information several comments were received:

- It was recommended that the Bill requires explanation about the risks of a medical intervention when a person is provided information, not just that risks are mentioned as being ‘common’ or ‘likely’.
- It was recommended that subparagraph 12(2)(a)(iii) be revised to omit ‘information about other kinds of treatment (for example, psychosocial care)’ and substitute ‘information about other kinds of care, support (including peer support) and treatment’.
- Intersex communities argued that there is a need to define what ‘sufficient information’ means.
- It was recommended to add the impact on fertility, and on sexual function and sensation to the Section 12(2)(a)(ii).
- Concerns were noted that the Section 12 did not include a clause relating to failure to obtain informed consent.

Medical professionals expressed concerns around waiting for competence and noted the complexities involved in assessing competence of young people.

Leaders from multicultural communities noted that multicultural parents will likely follow the doctor's advice and that they would be sensitive to any perception that their authority over children is reduced. It was also noted that culturally the age of adulthood can be different.

Submissions from human rights organisations also included support for the language of “supported decision-making”.

## Other issues raised

Other comments on the Bill were provided in addition to responses to the seven key questions that formed the basis for consultation. These comments are presented in no particular order:

- Multiple submissions noted the need for better psychosocial support to be provided.
- Comments were made about the need to produce community education resources once the legislation has passed.
- Many comments from human rights experts and intersex advocates noted the assumptions that people will be teased or bullied later in life are unsubstantiated as variations may not be known to others. They argued that one cannot justify medical interventions based on normalisation to prevent future bullying. Instead, this should be mitigated through prevention of bullying and approaches that affirm the person’s variation in sex characteristics.
- Regarding ministerial authority when making regulations, it was noted that this should be constrained to the Bill’s objectives. Other stakeholders suggested that the power for the Minister to intervene could be made similar to other legislation concerning children.
- Comments were made (mostly by medical professionals and parents) that the proposals in the Bill will create additional bureaucratic processes.
- Comments were made that it is important to ensure that gender affirming care for transgender children is not impeded by this legislation.
- In relation to the offence provisions, there were divergent views.
  - Medical professionals did not support a criminal offence, and also argued that the penalties were too severe.
  - Human rights advocates noted a disparity between the maximum penalty for the offences in the Bill, and the much higher penalties for female genital mutilation (FGM) in the *ACT Crimes Act* (1900), suggesting that the penalties in the Bill should be similar to these.
  - The criminal offence of removing a protected person from the ACT was described as difficult to police and would create inequity between the ACT and surrounding NSW, while limiting the ability to seek advice from specialists in other states.
  - One submission drew attention to higher penalties in laws regulating medical devices and included specific recommendations to increase proposed penalties.
  - One stakeholder recommended establishing an additional civil penalty for failing to receive informed consent from a person with decision-making capacity in order to provide a remedy for individuals subject to treatment without informed consent.
- Multiple comments were made in relation to the lack of definitions for concepts in the legislation. This included:
  - A lack of clarity around the definition of ‘interested party’ under the legislation.



- A lack of clarity around ‘easily reversible’, given the impacts of trauma from temporary or reversible physical treatments, potential costs involved and stigma that may prevent people from seeking reversal.
- Multiple comments related to additional considerations for the legislation. This included:
  - Comments were made about necessary considerations of the privacy concerns in the context of cloud data storage and data breaches.
  - Comments were made about a discrepancy in the years for records to be retained.
  - Recommendations made to add provisions regarding information sharing.
  - Comments made to consider including a mandatory reporting obligation with respect to emergency treatment.
  - Comments were made about consideration of mutual recognition of interstate schemes and treatment plans once other jurisdictions adopt similar legislation.
  - The Bill does not appear to declare the status of all subordinate laws used to prescribe relevant matters pursuant to the Bill. Thus, it is unclear whether they would be notifiable instruments or disallowable instruments.
  - A consideration needs to be given to the role of the public advocate.
- Intersex stakeholders recommended investment in research to hear from people with lived experience and their outcomes in the health system.
- Medical professionals recommended proper resourcing to support the legislation once adopted.
- Medical professionals who were against the legislation altogether proposed a range of alternatives. These included establishing an authority to collect data about current practices and identify deficiencies, a mandatory process rather than a legislative process, developing a set clinical practice guidelines and standards of care, establishing a national patient registry, and/or mandatory expert multidisciplinary team review for complex decision-making.
- A small number of stakeholders provided information about research in the area of long-term psychological effects of infant medical intervention. While some medical stakeholders suggested that early intervention is better because it limits the trauma of surgery on a child who won’t remember it, this was disputed by other experts. While there may be no conscious memory in children, there may be other physical and psychological effects. These stakeholders argued that there are merits to having a conscious care journey that can be verbalised through words.

## What’s Next?

The feedback from submissions, workshops, and meetings, together with other advice and research, will be used to improve the design of the legislation. It will also help determine how other elements of care and support for people with variations in sex characteristics are delivered.

You can email to request that you are updated on project as it progresses: [intersex@act.gov.au](mailto:intersex@act.gov.au).

To find out more about this project and other initiatives, policies and projects in Canberra visit [act.gov.au/lgbtiq](http://act.gov.au/lgbtiq).

## Glossary Of Key Terms

This glossary draws on the *Oxford Concise Medical Dictionary* (8<sup>th</sup> Edition) and the *Nelson Textbook of Paediatrics* (21<sup>st</sup> Edition), as well as extracts 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, and we have made minor adjustments to update language where possible.

**Androgens** are a group of sex hormones, including testosterone, that stimulate the development of male sex organs and male secondary sexual characteristics.

**Bladder Exstrophy** is a congenital abnormality in which the bladder fails to close during development, resulting in a baby born with an absent lower abdominal wall and the internal surface of the posterior bladder wall is exposed. It is associated with epispadias, total urinary incontinence, and undescended testes.

**Chordee** refers to acute angulation of the penis. It is associated with hypospadias.

**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). 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 people with variations in sex characteristics, there are variations in the configuration of the 23rd chromosome set. Phenotypes are produced by multiple chromosomes acting together.

**Cloacal Extrophy** is a condition in which an infant has the bladder and a portion of the intestines exposed outside the abdomen. In males the penis is either flat and short or sometimes split. In females the clitoris is split and there may be two vaginal openings. Frequently the intestine is also short and the anus may not be open.

**Congenital adrenal hyperplasia (CAH)** refers to a group of genetic differences 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 the testes fail to descend into the scrotum and are retained within the abdomen or inguinal canal.

**Endocrinology** is a medical specialisation dealing with the body's production, use and response to hormones.

**Epispadias** is a development difference in which opening of the urethra is on the upper surface of the penis.

**Gonads** are reproductive glands; the term can refer to either testicles or ovaries. Gonads in foetuses 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.

**Hyperandrogenism** is a hormonal difference involving the excessive secretion of androgen in females. It is commonly related to PCOS.

**Hypogonadism** is impaired function of the gonads, causing absence or inadequate development of secondary sex characteristics.

**Hypospadias** is a development difference 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 innate variations in sex characteristics. In this report, intersex is used to refer to communities and organisations that identify with and use this term.

**Klinefelter's syndrome** is a genetic difference in which there are three sex chromosomes, XXY. Affected individuals are male but may have small testes, little or no sperm production and atypical secondary sex characteristics.

**Mayer-Rokitansky-Küster-Hauser (MRKH)** is the congenital absence of the uterus and upper part of the vagina due to failure of development of the Müllerian duct.

**Müllerian duct** are paired ducts that form in the embryo. In females these ducts develop into the Fallopian tubes, uterus, and part of the vagina.

**Polycystic ovary syndrome (PCOS)** is a common hormonal difference in women, caused by an imbalance of reproductive hormones.

**Syndrome Specific Organisation** refers an organisation that provides support for a specific syndrome or group of syndromes that could be considered variations in sex characteristics.

**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.

**Wilms Tumor Suppressor Gene (WT1) Mutations** include rare genetic syndromes such as **Frasier Syndrome**, **Denys-Drash Syndrome**, and **WAGR** (Wilm's tumour, aniridia, genitourinary abnormalities, and mental retardation) **Syndrome**. They are characterised by several malformations present at birth which can include variations in sex characteristics such as ambiguous genitalia, depending on genes (such as **DAX1** and **SF1**).

**Variation in sex characteristics** 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. Other terms that may be used include intersex or disorder in sex development or differences in sex development, depending on the context.



Chief Minister, Treasury and Economic  
Development Directorate

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