



# PROHIBITION OF DEFERRABLE MEDICAL INTERVENTIONS ON INTERSEX PEOPLE

**Listening report on  
submissions received**

Chief Minister, Treasury and Economic  
Development Directorate

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# EXECUTIVE SUMMARY

The ACT Government is committed to ensuring all Canberrans are treated equally, and our laws should reflect these standards. As part of the Capital of Equality First Action Plan 2019-2021, the government is collaborating with intersex people, human rights organisations and healthcare professionals on a project working towards prohibiting deferrable medical interventions on intersex people in Canberra.

This work is based on recognition of the Darlington Consensus Statement on intersex human rights and exploring how it impacts on the ACT.

To inform the development of policy, consultation with experts and intersex community representatives across the ACT and Australia is being undertaken.

This listening report aims to share key insights from submissions received to an ACT Government discussion paper on the project [discussion paper](#) released between December 2020 and February 2021.

During this round of engagement, we asked for information and advice from identified key stakeholders on various aspects of how a prohibition could be framed to ensure it will work in practice.

The listening report does not serve as a government or directorate response to issues raised by stakeholders during the engagement and simply aims to provide transparency regarding the perspectives and issues received.

## Who engaged?

In total, 15 submissions were received from organisations across the health, human rights, LGBTIQ+ and legal sectors with relevant expertise and experience. Five other organisations endorsed submissions by others rather than providing their own. The feedback provided will help us to shape advice to government on how a prohibition could operate in Canberra.

## Key insights from stakeholders

### Common Ground

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

- The importance of multi-disciplinary teams in care and decision-making.
- Enhanced support for intersex children and their families.
- More data and research to support evidence-based decision making.

### Divergent Views

Submitters disagreed on the following issues:

- What is included as intersex? Views diverged on whether being 'intersex' can be considered an identity, or a quality of someone who has variations in sex characteristics.

Views diverged on whether the scope of intersex includes any variation in sex characteristics, or only people who are sexually ambiguous.

- What is in and out of scope? The medical interventions that should potentially be deferred, and the medical interventions that should be prohibited.
- Whether there should be regulation of medical interventions or outright prohibition.

#### Other themes that emerged

- Submissions discussed the basic principles and framework that should underpin care, as well as who should have decision-making powers. Themes that emerged were holistic care to ensure individual agency, family wellbeing, long-term support and bodily autonomy.
- Submitters disagreed on which practices were past or current. Health professionals asserted that inappropriate medical interventions were no longer practiced, while intersex submitters disagreed.
- Possible models for prohibition were put forward, ranging from outright prohibition to regulation of medical interventions.

#### **What's next?**

Feedback will be used to shape the plan on how prohibition of deferable medical interventions on intersex people could operate in Canberra. This listening report will support future community and stakeholder engagement on a model for intersex protections. Advice on a model is expected to be provided to the ACT Government Executive later in 2021.

You can stay up to date at: [act.gov.au/lgbtiq](https://act.gov.au/lgbtiq) or by e-mail [intersex@act.gov.au](mailto:intersex@act.gov.au)

## CONTEXT

In its [Capital of Equality Action Plan](#), the ACT Government committed to collaborate with intersex people, human rights organisations and healthcare professionals to form a plan on how prohibition of deferrable medical interventions on intersex people could operate in Canberra.

As part of this commitment, in December 2020 a Discussion Paper was circulated to expert stakeholders asking for feedback in response to a range of specific questions about how a prohibition might be designed. The Discussion Paper reflected the technical and complex nature of some of the issues that need to be addressed as part of the project. The discussion paper has been released for information at [act.gov.au/lgbtiq](https://act.gov.au/lgbtiq).

This report summarises for stakeholders key features of the responses the government received to the Discussion Paper.

## WHO RESPONDED?

Fifteen substantive submissions were received from individuals and organisations. These included a video recording of a discussion meeting convened by intersex organisations, which included eight participants, of whom seven identified as intersex / having variations in sex characteristics, and one as a parent of such a child.

The submissions were:

- 3 from individuals (including the video meeting)
- 12 from organisations.

There were:

- 8 from intersex and LGBTIQ+ backgrounds or organisations
- 6 from health professional backgrounds or organisations
- 1 other.

There were:

- 4 from ACT individuals and organisations
- 8 from national organisations or groups of individuals (including the video meeting)
- 3 from state-based individuals and organisations – all of them medical professionals who provide specialist care for intersex children from south-east Australia including the ACT.

One of the submissions was made by providing the organisation's submission to the Australian Human Rights Commission. In addition to the 15 submissions, five other organisations endorsed submissions by others rather than providing their own.

## WHAT WE HEARD – COMMON GROUND

Submissions all agreed that it is desirable to defer a range of medical interventions, leaving future decision-making options for individuals. This included some health professional organisations explaining that their current practice is to discourage or refuse requests for early interventions, such as gonadectomy, where it could be deferred. Intersex, LGBTIQ+ and human rights organisations supported deferral to ensure bodily autonomy of intersex people and to preserve future choices for individuals.

There were several other areas of common ground across most submissions. These include:

- The need for teams containing diverse skill sets to play roles in decision-making, rather than decisions sitting just with clinicians and the individual and/or their family.
- An urgent need for more funded psychosocial support for the children and their families; and
- A need for better data and more research to support evidence-based decision-making.

### The importance of teams in care and decision-making

There was widespread support for intersex care and decision-making to take place in a setting where a range of different professions and skills are present. Some submitters saw this as a team within the healthcare system, often referred to a multi-disciplinary team (MDT); others recommended a body independent of the health system but including clinical experts. For some it was advisory; other submitters saw it as having decision-making authority and/or oversight.

The kinds of skills and backgrounds that submitters thought should be involved varied. Suggested skills and perspectives included: psychology, psychiatry, counselling, social work, law, human rights, child advocacy, surgery, urology, endocrinology, genetics, ethics and cytogenetics. There was broad support for community representation to be included. For some submitters this meant representation from the broader community but having expertise or experience, such as in family law or human rights; for other submitters it meant representation by people with intersex variations.

It was not clear from submissions the extent to which care of children with variations in sex characteristics are currently overseen by MDTs. Submissions did not appear to indicate that intersex care was *required* to be channelled through MDTs, though most health professionals argued that this was where best practice care occurred.

### Support for children and families

Submitters placed importance on psychological and social wellbeing. Most submissions addressed this topic and said that psychological care and psychosocial supports are needed for children and their families. Many indicated that these currently are limited or absent due to a lack of resources. Submissions from health professionals said that this lack of resources meant not all patients being seen by a MDT were getting the psychological support that they should. This appears to be an issue across jurisdictions.

Submitters of all backgrounds recognised the benefits of families accessing peer and community supports. Several indicated that there should be increased resourcing of peer

support and advocacy organisations. The roles for peer and community supports could include providing affirming social support. It could give parents and children the encouragement and support to better assist children to form their own opinions and make their own future decisions about medical care.

## **Data and research**

There is widespread support for reforms to achieve better data collection, research and implementation of research findings. Submitters often referenced the limited availability of information about different variations in sex characteristics, and the very limited study of long-term outcomes of medical intervention on intersex people. Some stakeholders recommended establishment of a national patient registry that could support longitudinal studies. Other stakeholders focussed on the shortage of outcome studies, which leads to a lack of evidence to support clinical decision-making.

## **WHAT WE HEARD – DIVERGENT VIEWS**

Submitters were divided on several key points, including:

- What variations in sex characteristics should be considered as intersex and therefore in scope of the discussion;
- What medical interventions should be within the scope of any prohibition;
- Whether early medical treatment of some variations in sex characteristics is desirable; and
- Whether there should be a regulatory prohibition.

### **What is included as intersex?**

There were differences between submitters about what should be considered intersex (and therefore the subject of this work). There were two reasons for these differences. First, some submitters appeared to treat the term 'intersex' as being about identity, while others treated it as meaning a person who has variations in sex characteristics (not about whether they identified as intersex). While the term can be given different meanings, this project is concerned with how medical intervention occurs for people with variations in sex characteristics, regardless of how they identify.

The second reason that submitters had different views about what is intersex, was to do with how variations in sex characteristics affect each person's appearance. Some submitters thought a child is intersex only if the variation in their sex characteristics makes it difficult to assign a sex to the child – it is not clear whether to say they are a boy or a girl. For other submitters, intersex is broader than that: it includes all variations in sex characteristics that differ from prevailing cultural and medical norms for female or male bodies. In particular, these submitters include people whose bodies are subject to medical intervention to make them appear more 'typical' of the sex they have been assigned.

### **What medical interventions should potentially be deferred?**

There is a wide range of medical interventions made on the sex characteristics of children, including intersex children. Submitters talked about some of the interventions they thought should be deferred. Some of them also talked about the sorts of interventions that should continue to occur. Often this was raised because of concern about possible unintended

effects of a prohibition.

The sorts of interventions that most submitters thought should be deferred included surgery that risked reducing future fertility options; and non-essential surgery done to align a child's body with a sex of rearing. This could include procedures that are undertaken to 'normalise' the appearance of genitalia, such as labiaplasty or clitoroplasty.

Most submitters favoured deferring a much wider range of medical interventions. However, health professional submissions highlighted the complexity of decision-making around these interventions and the need to consider non-clinical factors to do with family preferences and socio-cultural factors that they considered could impact on the child's overall wellbeing.

Examples of medical interventions where there is potentially disagreement between submitters on how they should be approached included:

- Gonadectomy for non-functioning gonads;
- Surgery for hypospadias or for genital variations not associated with known genetic variations in sex characteristics; and
- Surgical intervention on girls with Congenital Adrenal Hyperplasia.

Examples of medical interventions that stakeholders raised that could be unintentionally captured by a prohibition, depending on how it was designed include:

- Oestrogen therapy for patients with Turner Syndrome;
- Hormonal replacement therapy in Congenital Adrenal Hyperplasia;
- Puberty blockers for children whose hormones are incongruent with their assigned sex/gender identity; and
- Male circumcision.

## **Is early intervention desirable?**

There was disagreement on whether early intervention was desirable, even in circumstances when it could be deferred. These divergent views were partly to do with how submitters thought decision-making should occur in the face of a poor evidence base, partly because of differences in what factors should take priority in decision-making; and differences in how non-clinical factors should be permitted to influence the timing of medical interventions.

Submitters took different approaches to how the lack of published evidence should affect decision-making about medical interventions for intersex children. Some submitters reasoned that the lack of evidence in favour of early rather than late intervention should favour later intervention, as deferral does more to preserve bodily autonomy and the decision-making options of the individual. Others treated the lack of evidence as meaning that moving to later interventions should be treated as "experimental". Of concern, no peer-reviewed studies that compared outcomes for subjects receiving early versus late intervention for the same intersex variations have been identified.

Early intervention was argued by some submitters to be supported by current practice and medical consensus statements; others argued that those same statements were silent on whether intervention should be early, which left decision-making to individual clinicians and



teams. One paper was cited indicating that young women with Congenital Adrenal Hyperplasia preferred early surgery over surgery in adolescence, but the submitter noted evidence of this kind is rare. Another submission critiqued the methodology of two of the few studies in this field.

Several submitters expressed concern that non-clinical or non-therapeutic rationales were sometimes supporting early intervention. They argued this was undesirable and risked decisions not being consistent with human rights obligations to children. They said that this was further complicated by a lack of clarity around what constitutes ‘therapeutic’ treatment or ‘medically necessary’ intervention. Several submitters said policy around early intervention needed to change because courts were currently failing, due to poor judgement around what is medically therapeutic.

## **Should there be a prohibition?**

While all submitters favoured deferral of a range of medical interventions on intersex children, they were divided over whether and how to support this with a prohibition. Overall, most submitters that weren’t health professionals favoured a prohibition, but most from health professional organisations did not.

Arguments made by submitters in favour of a prohibition include:

- Current approaches lead to human rights of children being violated;
- Current practice can cause harm to children with variations in sex characteristics;
- Published “consensus statements” in the medical literature will continue to guide medical practice unless it is regulated, and these statements do not clearly advise against early interventions; and
- United Nations convention committees have examined the issue and call for Australia to prohibit intersex medical interventions that occur without consent of the individual.

Most health professional submissions opposed any prohibition; all other stakeholders support one. Health professional arguments against prohibition focussed on:

- Complexity of individual cases requiring a more flexible approach than legislation allows;
- Difficulty of envisaging a prohibition that would not capture a wide range of procedures and situations that it should not cover (including procedures not related to a person having variations in sex characteristics);
- The cost and trauma to families and health professionals of having to go through courts and other bureaucratic processes at what is a difficult time for them; and
- Recent advances in practice and the use of multi-disciplinary teams to support decision-making have addressed the issues sufficiently.

As noted earlier, there was widespread support for the use of teams in medical decision-making for intersex people. One of the ways some submitters expressed this was to favour a requirement that decision-making be channelled through a team. Support for mandated advisory or oversight team was expressed by most submitters, including some health care professionals.

## OTHER ISSUES

### Goals of care and decision framework

There were different suggestions about the basic principles that should underpin care, and the broad approach to its regulation. Most health professionals focused on holistic outcomes for a child, which they suggested should include family unit wellbeing and a range of other non-clinical factors. Other submitters referred to long-term or future welfare of the child, often including a focus on bodily autonomy and the rights of the person to be involved in decisions about their body, including to make future decisions.

Some health professional submissions favoured a clinical framework for decision making, while all others favoured embedding clinical factors within a human rights framework for decision-making.

### Past practices or current practices?

Most health professional submissions asserted that the inappropriate medical interventions being addressed in this policy discussion are historical and that no-one undertakes care in those ways anymore. Some stated that the current discussion is an artifact of activism by a minority of people who experienced poor care in the past. Those submissions were often critical of those past practices and argued that they are the reasons both for changes that have occurred to date, and why it is important for intersex care to take place in experienced multi-disciplinary teams.

Intersex and LGBTIQ+ organisations argued that these practices are current, that there is a lack of evidence about changes in practice, and a lack of transparency around what current treatments are occurring.

### Possible models

Two submissions from organisations with experience in human rights and family law were helpful in putting a proposed prohibition in legal context and suggesting how it might be constructed. One of those submissions set out legal detail around why a prohibition would not be legally radical and would be consistent with orthodox legal thinking about child welfare.

Other models that submitters suggest be examined included the Queensland regime prohibiting cosmetic surgery on children; and recent Icelandic legislation prohibiting deferrable medical interventions on intersex children.

## CONCLUSION

Submitters engaged carefully and intensively with the range of questions in the Discussion Paper, and the Office of LGBTIQ+ Affairs is extremely grateful to individuals and organisations for their commitment to address this issue of importance to intersex Canberrans and the broader community.

The Office of LGBTIQ+ Affairs will take all feedback into account. We will work to design possible options for implementing a prohibition of deferrable medical interventions that consider:

- The concerns and questions raised by submitters;
- The implementation of other relevant regulatory regimes in other jurisdictions, such as those suggested by submitters; and
- Examples provided by submitters of medical treatments and issues that a prohibition could inadvertently affect.

The next stage of this project is planned to involve testing with experts and stakeholders of one or more potential options for a prohibition of deferrable medical interventions. Stakeholders who made submissions in response to the Discussion 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.

**Bodily autonomy** is the right to governance over our own bodies and emphasises the importance of making fully informed decisions about one's physical self.

**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** 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.

**Cytogenetics** is the branch of genetics that studies the structure of chromosome material and the study of diseases caused by structural and numerical abnormalities of chromosomes.

**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 fetus. 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.

**Labiaplasty** is a surgical procedure to modify, usually by reducing the size of the labia, the folds of flesh and skin that surround the female genitals.

**Longitudinal study** is a research design that follows the subject over time with continuous or repeated monitoring of risk factors or health outcomes.

**Oestrogen therapy** is treatment with the hormone oestrogen to increase the amount of oestrogen in the body.

**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.

**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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