



KEY ISSUES IN THE PROHIBITION OF DEFERRABLE MEDICAL INTERVENTIONS ON INTERSEX PEOPLE

Discussion Paper

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Economic Development Directorate

December 2020

This discussion paper is for consideration by individuals and organisations with expertise and experience in intersex rights and care

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WHAT THIS PAPER IS ABOUT

People who are intersex, or have differences of sex development, are born with sex characteristics (such as genitals, gonads or chromosome patterns) that do not fit typical binary notions of male or female bodies.¹ This diverse population ranges from individuals requiring lifelong care for symptoms associated with their variations, to those who require no specialised care at all. There are many committed medical professionals who provide advice and care to intersex people. There are also issues with ensuring that care respects choices and identities, particularly of young intersex people. This has led the ACT government to commit to form a plan on how prohibition of deferrable medical interventions on intersex people could operate in Canberra.

This discussion paper seeks your input. The goal is to better help intersex people, families, health professionals and advocates to make decisions around intersex lives and care.

This discussion paper is designed to consult with individuals and organisations with expertise and experience relating to intersex rights and care. It assumes the reader is familiar with issues around medical interventions on intersex people. The paper is based on published literature, the experience of other jurisdictions in considering this issue, and information from intersex people and their families in Australia about their experiences.

This discussion does not presume what policy changes will be implemented. It is intended to help frame advice to government.

This work is supported by the government's [Capital of Equality Strategy](#). Relevant aims of this Strategy are to deliver outcomes including:

- Services that are safe, inclusive and appropriate;
- LGBTIQ+ people have equality before the law, equal protection and benefits of the law; and
- Ensuring LGBTIQ+ human rights are reflected and respected.

The [First Action Plan](#) under the strategy identifies the importance of:

- Collaborating 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;
- Providing LGBTIQ+ people with access to services; and
- Ensuring that LGBTIQ+ people receive support that is both appropriate to their experience and responsive to their needs across all stages of life.

This project on prohibition of deferrable medical interventions is not the only way the ACT Government is working to better support intersex Canberrans. It sits alongside other projects, including funding peer support, the development of intersex information resources for use in our schools, and undertaking a Health Scoping Study to better understand how services can be improved for LGBTIQ+ Canberrans.

It is acknowledged that the term “intersex” is an umbrella term: people are many things, and their intersex characteristics are just one dimension. Some people use the term intersex, while others do not. Other terms may also be preferred by different stakeholders, and can be appropriate, depending on the context. These include variations of sex characteristics, difference (or disorders) of sex development (DSD)

¹ United Nations High Commissioner, *Fact sheet: intersex*. See also the Darlingtong Statement.

or dsd), and terms applied to specific genetic or chromosomal variations. In this paper, intersex refers to these variations; it is not used to refer to how a person identifies.

WHY CHANGE IS NECESSARY

There are several reasons to reform the approach to care for intersex people. First, international research indicates that the circumstances around contemporary medical care for intersex people present ongoing challenges including the risk of violation of the human rights of intersex children:

- Prevailing cultural expectations and medical practice include assignment of sex and gender at the earliest opportunity;²
- Stress, anxiety, cultural norms and a lack of definitive medical guidelines all influence parental decision-making, often in favour of early medical intervention;³
- Gender ‘normalising’ surgeries are conducted on young children;⁴
- There is no consensus in the medical literature around optimal approaches to surgical intervention on people with intersex variations;⁵ and
- Poor evidence for the long-term outcomes of many early medical interventions means that for some intersex people, the literature supports later medical intervention, including when the patient can make their own decisions.⁶

Second, from consultation with health consumers and health practitioners in Australia, it is known that:

- Some children are being excluded from decision-making about their bodies in which they have the capacity to engage;

² See for example Lee, P.A. et al., 2016. ‘Global disorders of sex development update since 2006: perceptions, approach and care’, *Hormone Research in Paediatrics*, vol. 85, pp.168-170, 173-176; Cresti, M. et al., 2018, ‘Intersexual births: the epistemology of sex and ethics of sex assignment’, *Bioethical Inquiry*, vol. 15, pp.557-568; Kearsey, I. and Hutson, J.M., 2017, ‘Disorders of sex development (DSD): not only babies with ambiguous genitalia. A practical guide for surgeons’, *Pediatr Surg Int.*, vol. 33, pp.355-361.

³ See for example Rolston, A.M. et al., 2015, ‘Parental reports of stigma associated with child’s disorder of sex development’, *Int J Endocrinol*, article ID 980121; Wolfe-Christensen, C. et al., 2017, ‘Changes in levels of parental distress after their child with atypical genitalia undergoes genitoplasty’, *Journal of Pediatric Urology*, vol. 13, pp.32.e1-32.e6; Markosyan, R. and Faisal Ahmed, S. 2017, ‘Sex Assignment in Conditions Affecting Sex Development’, *J Clin Res Pediatr Endocrinol.*, vol. 9(Suppl 2), pp.106–112; Timmermans, S. et al., 2019, ‘Gender destinies: assigning gender in disorders of sex development-intersex clinics’, *Sociology of Health & Illness*, vol. 41(8), pp.1520-1534; Davis, G., 2015, *Contesting intersex*, New York University Press, chapter 5.

⁴ See for example Rolston et al., 2015, above; Wolfe-Christensen et al., 2017, above; Yankovic, F. et al., 2013, ‘Current practice in feminizing surgery for congenital adrenal hyperplasia; a specialist survey’, *Journal of Pediatric Urology*, vol. 9, pp.1103-1107; Wisniewski, A.B. et al., 2019, ‘Management of 46,XY differences / disorders of sex development (DSD) throughout life’, *Endocrine Reviews*, vol. 40(6), p.1561; Australasian Paediatric Endocrine Group, 27 June, 2013, *Submission of the Australasian Paediatric Endocrine Group to the Senate Inquiry Into the Involuntary or Coerced Sterilization of People with Disabilities in Australia: Regarding the Management of Children with Disorders of Sex Development*.

⁵ See for example Vora, K. and Srinivasan, S., 2020, ‘A guide to differences/disorders of sex development/intersex in children and adolescents’, *Australian Journal of General Practice*, vol. 49(7).

⁶ See for example Mouriquand, P.D.E. et al., 2016, ‘Surgery in disorders of sex development (DSD) with a gender issue: If (why), when, and how?’, *Journal of Pediatric Urology*, vol. 20, pp.1-11; Carmack, A. et al., 2015, ‘Should Surgery for Hypospadias Be Performed Before An Age of Consent?’, *The Journal of Sex Research*, pp.1-12.

- Families are not always offered sufficient information that respects the human rights of the child, and sometimes do not have access to adequate support and expertise;⁷ and
- In the largest survey of intersex people conducted in Australia, published in 2016, the results showed that “One fifth of the participants had been given no information at all about any surgical or hormonal treatments they had received and the majority were not told about risks related to the interventions, their right to not have these often life-changing treatments or other related information. Participants reported various physical, mental and psychological impacts from treatments.”⁸

Third, United Nations committee reports on Australia have called for Australian jurisdictions to legislate to prevent deferrable medical interventions on intersex children.⁹

GOALS FOR THIS PAPER

To ensure intersex children’s identities are respected and celebrated, and that they receive the best available care and support, the ACT government is looking at ways to manage intersex medical interventions that are different to some past and current practice. Managing health care for intersex people can be complex because it may occur across jurisdictional boundaries, for those individuals who require access to highly specialised care that is only available at a limited number of locations around the country. Any changes will need to take account of this.

Through this paper, you are invited to apply your expertise to some key issues that need to be resolved. There are different options for how to manage intersex care, some of which potentially conflict with each other. This is in part because, historically, guidelines have been given widely differing interpretations.

There have been several recent inquiries and papers produced that provide more extensive discussion of many of the key issues in this field. These include:

- The Australian Human Rights Commission’s July 2018 discussion paper, [*Protecting the Human Rights of People Born with Variations in Sex Characteristics in the context of Medical Interventions*](#)
- Victoria’s Health and Human Services March 2019 paper, [*Health and wellbeing of people with intersex variations - Information and resource paper*](#)
- Tasmania Law Reform Institute’s June 2020 final report 31, [*Legal Recognition of Sex and Gender*](#)

This paper does not seek to revisit all the ground covered by those publications. It does not attempt to cover every issue that will need to be addressed to improve governance or delivery of intersex medical care. It is focussed on a selection of issues that directly affect the design of options to prohibit deferrable medical interventions in the ACT, on which your input can assist.

The issues being explored in this discussion paper are:

- Principles guiding intersex care
- The scope of medical interventions that should be covered
- What the exceptions should be, where medical intervention is okay
- Whether the population needs to be defined for the purpose of this prohibition, and if so, how
- Consent and its alternatives, particularly alternative options for supporting medical decisions

⁷ See also Davis, G., 2015, *Contesting Intersex*, New York University Press, chapter 5; Lundberg, T. et al., 2017, ‘From knowing nothing to knowing what, how and now: parents experience of caring for their children with congenital adrenal hyperplasia’, *Journal of Pediatric Psychology*, vol. 42(5), pp.520-529.

⁸ Jones, T. et al., 2016, *Intersex: Stories and Statistics from Australia*. Cambridge, UK: Open Book Publishers, p.3.

⁹ United Nations Committee on the Rights of the Child, November 2019, *Concluding observations on the combined fifth and sixth periodic reports of Australia*, CRC/C/AUS/CO/5-6; Concluding Observations: UN Report on Australia’s Review of the Convention on the Rights of Persons with Disability (CRPD), 24 September 2019.

Each section below looks at these five areas and includes some questions to which you can respond. The final section of the discussion paper explains options for providing your response.

PRINCIPLES GUIDING INTERSEX CARE

There are different ways that the goal of managing medical interventions for intersex people can be described. Examples include to uphold children's human rights, to prevent harm, to deliver optimal health care outcomes, or to ensure child welfare. Objectives can overlap, mutually reinforce each other, or can potentially be in conflict.

Several key human rights conventions are relevant to the experience of intersex people. The Convention on the Rights of the Child (CRC) says that:

*States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.*¹⁰

The Convention on the Rights of Persons with Disabilities is important because of its emphasis on equality in how people with different bodies are treated, and through the work of the UN looking at medical intervention, including on intersex people. The preamble recognises "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices".

Two 2019 reports based on those conventions have explicitly recommended both principles and pathways for action to protect intersex people in Australia:

- A United Nations Committee on the Rights of the Child report states Australia should be: "explicitly prohibiting coerced sterilization or unnecessary medical or surgical treatment, guaranteeing the bodily integrity and autonomy of intersex children and providing adequate support and counselling to families of intersex children"¹¹; and
- A United Nations (UN) report on the Convention on the Rights of Persons with Disability that proposes Australia "Adopt clear legislative provisions that explicitly prohibit the performance of unnecessary, invasive and irreversible medical interventions, including surgical, hormonal or other medical procedures on intersex children before they reach the legal age of consent"¹².

Human Rights instruments explicitly place the rights of children and people with disability alongside the responsibilities of parents or guardians in providing care and decision-making for children. For example the CRC refers to parents or guardians having "the primary responsibility for the upbringing and development of the child"¹³ and considers that governments "shall respect the responsibilities, rights and duties of parents... legal guardians or other persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance in the exercise by the child of the rights recognized in the present Convention."¹⁴

The intersex medical literature sometimes does not make explicit the principles or objectives of care, or refers to objectives of particular subsets of treatment:

¹⁰ CRC Article 12.

¹¹ United Nations Committee on the Rights of the Child, November 2019, *Concluding observations on the combined fifth and sixth periodic reports of Australia*, CRC/C/AUS/CO/5-6*, para 31(b).

¹² Concluding Observations: UN Report on Australia's Review of the Convention on the Rights of Persons with Disability (CRPD), 24 September 2019, Paragraph 34(b).

¹³ CRC Article 18.

¹⁴ CRC Article 5.

- In a few papers, there are references to “quality of life”. While mostly undefined,¹⁵ in some cases this is determined by reference to patient-reported experience and outcomes.¹⁶
- Current international guidance on congenital adrenal hyperplasia (CAH) offers no overall objectives. In a paragraph confined to surgical aspects, it refers to goals of “preserving functional anatomy and fertility”.¹⁷ The paper sometimes uses the concept of a “balance of benefits and harms”, but not consistently, while also (though only in reference to surgery) referring to “presumed” benefits.¹⁸
- Published medical guidance often includes a goal to make an intersex person as ‘normal’ as possible,¹⁹ but this is not always articulated in either the literature or in practice. Further, as one article noted, “It is difficult to study expectations when patients and families may wish to be ‘normal,’ and providers may have a different definition of what that means.”²⁰
- In some literature, assigning the sex of a baby is a stated priority²¹ but in others, sex assignment is discouraged.²²

The way objectives are translated into practice when guiding or regulating care of intersex people varies considerably. Examples of stated objectives in this area include:

- Maltese law describes a “right to bodily integrity and physical autonomy”²³ with the Darlington Statement similarly referring to “bodily integrity physical autonomy and self-determination” (clause 5)
- Draft legislation in California framed it as a “right of people born with variations in their physical sex characteristics to participate in decisions about surgery and other medical treatments or interventions on their physical sex characteristics.”
- A major medical statement published in 2016 describes the overarching objective as “fostering the overall well-being of the child and future adult”.²⁴
- A major treating hospital does not set objectives itself, but aims to “provide optimal care, as recommended in international clinical guidelines”.²⁵

The complexity in balancing different objectives is evident from a major update on intersex health care published in 2016, which lists nine different principles and processes that can be followed in this field:

(1) minimising physical and psychosocial risk; (2) preserving potential for fertility; (3) upholding the individual’s rights to participate in decisions that will affect their now or later; (4) leaving options open for the future by avoiding irreversible treatments that are not medically necessary until the individual has the capacity to consent; (5) providing psychosocial support and peer support; (6) supporting the individual’s healthy sexual and gender identity development; (7) using a shared

¹⁵ See for example, Lee et al., 2016, above.

¹⁶ See for example Gravholt, C. H. et al., 2018, ‘Klinefelter syndrome: Integrating genetics, neuropsychology, and endocrinology’, *Endocrine Reviews*, vol. 39(4), pp.389-423.

¹⁷ Speiser, P.W., et al., 2018, ‘Congenital adrenal hyperplasia due to steroid 21-hydroxylase deficiency: an Endocrine Society clinical practice guideline’, *J Clin Endocrinol Metab.*, vol. 103, p.4047.

¹⁸ Speiser et al., 2018, above, p.4066.

¹⁹ See, for example, Baskin, L.S., 2017, ‘Restoring normal anatomy in female patients with atypical genitalia’, *Seminars in Perinatology*, vol. 41(4), pp.227-231.

²⁰ Graziano, K. and Fallat, M.E., 2016, ‘Using Shared Decision-Making Tools to Improve Care for Patients with Disorders of Sex Development’, *Advances in Pediatrics*, vol. 63(1), p.476.

²¹ See, for example, Markosyan, R. and Faisal Ahmed, S., 2017, ‘Sex Assignment in Conditions Affecting Sex Development’, *J Clin Res Pediatr Endocrinol.*, vol. 9(Suppl 2), pp.106–112; Woodward, M. and Roberts, R., 2016, ‘Disorders of sex development’, *Surgery*, vol. 34(12), pp.633-638.

²² Witchel, S.F., 2018, Disorders of sex development, *Clinical Obstetrics & Gynaecology*, Vol. 48, pp. 90-102.

²³ *Gender Identity, Gender Expression and Sex Characteristics Act 2015* (Malta), s.3(1)(d).

²⁴ Lee et al., 2016, above, p. 176.

²⁵ Royal Children’s Hospital, Melbourne, Differences of sex development, <https://www.rch.org.au/endo/differences-of-sex-development/>

decision-making approach that respects the individual's and parents' wishes and beliefs; (8) respecting the family and parent child relationships, and (9) providing patients with full medical information appropriate for age, developmental stage and cognitive abilities.²⁶

Questions:

(1) What should be the objective(s) of intersex health care?

(2) What should be the stated objective of any prohibition of deferrable medical interventions on intersex patients?

(3) How should the objective of a prohibition be framed, so it is inclusive of both the rights of the child and the rights and responsibilities of parents and guardians to act in their children's interests?

SCOPE OF TREATMENT

For those intersex people unable to give consent, there are different approaches to describing the scope of medical interventions that could be prohibited or deferred. Similarly, there is a wide divergence in approaches to describing the circumstances that define exceptions to that scope.

Based on concepts from a range of sources, here are five ways in which proposals could be framed to describe the potential scope of what could be prohibited or regulated:

1. invasive or irreversible medical procedures that modify sex characteristics
2. removal of tissue below skin from internal or external genitalia (or gonads)
3. irreversible sex assignment treatment or surgical intervention on the sex characteristics of a minor with a diagnosed variation in their sex characteristics
4. unnecessary, invasive and irreversible medical interventions, including surgical, hormonal or other medical procedures
5. sex assignment treatment and/or surgical intervention on the sex characteristics of a minor, if that treatment and/or intervention can be deferred until the person to be treated can provide informed consent.

All of these proposals can raise issues.

Sex characteristics?

If "sex characteristics" is used when defining scope, it will need to be defined. In any kind of regulatory setting, definitional clarity is essential in determining the parameters of the regulation.

In biology, primary sex characteristics refers to the genitals and reproductive organs, while secondary sex characteristics means non-reproductive characteristics determined by sex hormones. Option 2 appears to suggest only primary sex characteristics should be the subject of a prohibition, while options 1 and 5 would imply both primary and secondary characteristics should be in scope.

The Yogyakarta Principles plus 10 define them as:

*... Each person's physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty.*²⁷

²⁶ Lee et al., 2016, above.

²⁷ Yogyakarta Principles plus 10, As adopted on 10 November 2017, Geneva, http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf

Malta's *Gender Identity, Gender Expression and Sex Characteristics Act 2015* defines sex characteristics as:

The chromosomal, gonadal and anatomical features of a person, which include primary characteristics such as reproductive organs and genitalia and/or in chromosomal structures and hormones; and secondary characteristics such as muscle mass, hair distribution, breasts and/or structure. (section 2)

The ACT's Discrimination Act definition of sex characteristics is that it:

- (a) means a person's physical features relating to sex; and
- (b) includes—
 - (i) genitalia and other sexual and reproductive parts of the person's anatomy; and
 - (ii) the person's chromosomes, hormones and secondary physical features emerging as a result of puberty.

Questions:

(4) Should modification of sex characteristics be part of the criteria that define what is in scope of a prohibition?

(5) If so, how should "sex characteristics" be defined?

Removal of tissue?

Making "removal of tissue" part of the definition would appear to place all non-surgical treatments (and some major surgical treatments) outside the scope. This would also appear to exclude hormone and other types of treatments, even if they were irreversible. There is also a concern that the phrase "removal of tissue" would exclude cosmetic interventions such as clitoral recession that may alter but not remove tissue, however this could be stated as within the scope in legislation.

Questions:

(6) Should a prohibition address gonadal surgery, other surgical and/or non-surgical medical interventions?

Deferrable or irreversible?

There is significant overlap between various concepts that arise regularly in these discussions: including deferability and irreversibility.

Part of the purpose of a prohibition on certain interventions is to allow them to be deferred until a person can consider them and make a decision themselves. The concept of a medical intervention being deferrable is not always simple. Deferring a treatment decision may be an ongoing discussion involving an intersex person, their parents and treating health professionals rather than a single point-in-time decision. An individual's health circumstances can change, in turn changing the need for intervention. There is no medical consensus around whether and when to perform some procedures on intersex individuals: different medical practitioners will express different views about whether something can or should be deferred.

It is not clear whether "deferrable" is an important part of the definition of what should be regulated, given that there are also non-deferrable treatments for which children's participation in decision-making is possible, and desirable for the protection of their human rights, but not always currently occurring.

The word “irreversible” is often used when seeking to define the scope of regulated treatments. Some procedures modify sex characteristics but could (sometimes with effort and risk) be reversed: examples include some hormone therapies. Interventions of these kinds on children (including adolescents) have been condemned by some as violating children’s rights, but if they are reversible, they could lie outside a prohibition that was limited to “irreversible” procedures.

Questions:

(7) Should a definition of the scope of a prohibition refer to treatments that are deferable or irreversible, or should it use other concepts to define what treatments should be in scope? Why?

Diagnosis?

The third option listed under “scope” above refers to “diagnosed variation”. This phrase assumes a medicalised definition of intersex. This phrase may be proposed in order to differentiate medical treatment for reasons associated with a person’s intersex status, from treatments on non-intersex people or for reasons that are unrelated to intersex status, but which involve medical intervention affecting sex characteristics. If the scope relies on a diagnosis, this would create an issue of deciding what diagnoses are to be classified as intersex, and who provides the diagnosis. This is a point of debate within the literature. There is also a question of how the prohibition would operate for cases where there was no diagnosis. This could be interpreted to mean that no diagnosis means the prohibition does not apply. There is a question about whether this is an appropriate outcome. Nevertheless, a system will be required that permits medical interventions that involve surgery or other treatment of genitals or hormones for reasons that have nothing to do with intersex status, such as to manage injuries.

Questions:

(8) Should inclusion in scope depend on having a diagnosed variation in sex characteristics?

(9) How should a definition be crafted to allow health professionals to undertake treatments that affect sex characteristics, but which are being undertaken for reasons unrelated to intersex status?

EXCEPTIONS

Here are three different ways that could be used to describe exceptions that would allow medical intervention that would otherwise fall within the scope of a prohibition or a requirement to defer treatment:

1. Unless necessary to avoid serious, urgent and irreparable harm to that person
2. Unless there is risk to the physical health or fertility of the child
3. Unless it is medically necessary to protect life, to prevent significant illness or significant disability or alleviate significant pain, where illness, disability and pain should be considered with reference to both physical and mental health

Defining the range of exceptions

When proposing a range of exceptions, it is important to find a definition that is not interpreted too narrowly or too widely, compared to what the definition seeks to target. There is a known issue in this field with psycho-social or purported mental health-based reasons being considered ‘therapeutic’ and used to support ‘normalising’ treatments, in a way potentially not compatible with a child’s human rights. Exceptions would need to be defined in a way that avoided this problem.

- In the above examples, option one refers to “avoid serious, urgent and irreparable harm”, while option three refers to “prevent significant illness or significant disability or alleviate significant pain”, including mental illness, disability or pain.

- In an approach like option one, is there a risk that a health issue that is not “urgent” and therefore fails that test, would not get acted upon even though it might be “serious and irreparable” and well-known from the literature?
- In an approach like option three, is there a chance that every decision-making factor, including psycho-social factors such as the inferred effects of a child appearing different or functioning differently to their peers, will be covered by exceptions, meaning there are no limitations being applied in practice?

“Medically necessary” presents similar issues. Determining what is “necessary” involves subjective judgement. When made by individual health professionals or small teams, those judgements will reflect what they have come to think of as appropriate practice. There are some life-threatening medical conditions requiring procedures the medical necessity of which are not in question. However, others are hotly disputed, with some suggesting appropriate medical practice includes surgery for psychosocial reasons,²⁸ while others reject this as unnecessary.²⁹ As a recent Victorian discussion paper noted:

In part, this criticism relates to a lack of clinical or directive protocols accompanying the principles and uncertainty around the degree to which clinical decisions have been subject to independent oversight. It also relates to differing interpretations of what constitutes medical need and what types of treatment are in the long-term interests of individuals.³⁰

If a term such as “medically necessary” is used, then there may then need to be an independent system for determining what this means.

Question:

(10) How should exceptions be described to allow clarity while avoiding overly wide interpretation of exceptions?

HOW AND WHY SHOULD INTERSEX BE DEFINED?

As the previous sections have outlined, if a policy is to prohibit deferrable medical interventions for intersex people, it needs in some way to describe to whom, or in what circumstances, the policy would apply. Definition is important so that children, families, health professionals and regulators know what supports to access, what processes to follow, and whether a regulatory framework applies to them.

It is possible to design a policy that applies to intersex people or conditions. However, there is no fixed definition of intersex.³¹

A range of biologically or genetically defined conditions is frequently associated with intersex. Most articles discussing intersex people will list many of these, such as Congenital Adrenal Hyperplasia (CAH) and Androgen Insensitivity Syndrome (AIS). However,

- there can be disagreement about whether a variation is intersex;

²⁸ See for example Royal Children’s Hospital, 2013, Submission on the involuntary or coerced sterilisation of people with disabilities in Australia. Senate Community Affairs References Committee.

²⁹ For discussion see Davis, G., 2015, *Contesting Intersex*, New York University Press.

³⁰ Department of Health and Human Services (Victoria), 2019, *Health and wellbeing of people with intersex variations - Information and resource paper*, p.37.

³¹ World Health Organisation Genomic Resource Centre, Gender and Genetics, <https://www.who.int/genomics/gender/en/index1.html>

- people with these variations may or may not refer to themselves as intersex; and
- not everyone with some of these variations shows variation in physiological sex characteristics.

An alternative approach to that of defining the scope of “intersex” for the purpose of regulating medical interventions, is to focus on providing support or protection in particular *circumstances*, or following particular *principles*, rather than by defining a *category of people or conditions*. One approach is to implement a rights-based framework that does not need to be applied only to a particular population (such as children with particular genetic or medical characteristics). This circumstances-based approach is implied in clause 7 of the Darlington Statement, which proposes:

prohibition as a criminal act of deferrable medical interventions, including surgical and hormonal interventions, that alter the sex characteristics of infants and children without personal consent.

Clause 7 does not specify a group to which the rule should apply, instead proposing universal prevention of alteration of sex characteristics without consent. This could for example extend to female or male circumcision. This is also the case in Malta’s *Gender Identity, Gender Expression and Sex Characteristics Act 2015*. However, elsewhere the Darlington Statement proposes a governance framework that would apply to a category of people: “persons born with intersex variations”:

the provision of alternative, independent, effective human rights-based oversight mechanism(s) to determine individual cases involving persons born with intersex variations who are unable to consent to treatment, bringing together human rights experts, clinicians and intersex-led community organisations. (clause 22).

The Darlington statement therefore recognises both a circumstance-based approach and a category-based approach. Clause 22 recognises the scope for an intersex-specific governance framework. If the ACT Government designs a prohibition on certain medical interventions for intersex children, then an appropriate definition of intersex will be needed.

Questions:

(11) Should the regulation of medical interventions be based on a definition of “intersex” as a category of person, or should it be designed based on circumstances or principles?

(12) If regulation of medical intervention should be based on intersex status, how should intersex be defined?

(13) If a prohibition is based on circumstances (e.g. “alteration of sex characteristics”) or principles (e.g. “with the consent of the individual”), rather than limited to a category of people, how would such a definition affect cases not related to intersex status, such as male circumcision?

CONSENT AND DECISION-MAKING

Consent is the agreement by one person to the plans or actions of another. In the context of medical care for intersex people, consent is important because agreement is often sought from someone – usually parents – to medical intervention on a child prior to adulthood. That intervention may be surgical, hormonal, psychological or physical and, depending on individual circumstances, may be proposed from shortly after birth through to adolescence.

One of the reasons to defer some medical interventions for intersex people is to allow children to make decisions around their own bodies and to give consent when they are able to.

Why consent matters

Previous sections have discussed a possible range of treatments that should be prohibited or deferred until a person can give their own consent. How consent is understood and given is important for intersex people because medical intervention is commonly proposed before the child has the capacity to give legal

consent. Some of those interventions may be irreversible in nature, may come with significant risks (as may not proceeding with them), and may involve intentionally altering sex characteristics. Some decisions may be influenced by the child's theorised gender identity, sometimes when they are too young for gender identity to be able to be inferred from anything the child themselves can express.

The Darlington statement refers to “personal consent”, which may reflect two kinds of experience of some intersex people that have been identified during this project:

- that parents sometimes seek, or are persuaded by medical practitioners, to support interventions intended to physically ‘normalise’ a child; and
- children with the ability to participate in treatment decisions are sometimes not informed about, or involved in, those decisions by their families or treating doctors.

Research also indicates that, while parents may agree to medical procedures, sometimes fully informed consent – consent based on a full range of information, supports and understanding – is not always secured.³²

There are therefore questions that need to be considered around what consent means, and when and how it can be given.

Questions:

(14) How can we best support the consent of a parent to make choices that preserve the consent of the child in a medical setting??

(15) What if any procedural requirements should be met in order to consider that consent is freely given and fully informed?

Are other supports or methods needed for intersex medical decision-making?

Consent is one of several concepts involved in the making of medical decisions for and by intersex children and their families. Some of those decisions can be delayed until a child can make them themselves. However, a decision-making framework is needed for all decisions, including those that cannot be deferred.

Some alternative approaches to guiding decisions have proved problematic. “Best interests of the child” has not always been useful because, while intended to put the child at the centre of the decision-making, it remains about decisions made *for* the child, rather than *with* them. “Best interests” has been a subjective term left open to interpretation by whomever the decision-maker might be. It also has been argued to put parental decision-making about some decisions on a different footing to other parental decisions with just as many consequences for the child. In judicial settings, “best interests” has resulted in some controversial outcomes potentially incompatible with the approach envisaged in the Darlington Statement.³³

The distinction between “therapeutic” and “non-therapeutic” decisions has been argued to have failed in intersex cases. This is similarly because there is no reference frame other than a decision-maker’s assertion of whether an action is therapeutic, and no independent criteria for what therapeutic means. In this regard, it presents the same issue as the term “medically necessary”.

³² See for example Roen, K., 2019, ‘Intersex or diverse sex development: Critical review of psychosocial healthcare research and indications for practice’, *The Journal of Sex Research*, vol. 56(4-5), pp.511-528.

³³ See for example *Re: Carla (Medical Procedure)* [2016] FamCA 7.

In some contexts, it may be desirable to have an explicit decision framework, potentially including supports and/or a decision-making or advisory body. One example is the formalised use of independent or support persons in decision-making. In guidelines on 'will, preferences and rights' developed by the Australian Law Reform Commission, this is set out:

In assisting a person who requires decision-making support to make decisions, a person chosen by them as supporter must: support the person to express their will and preferences...

Where a representative is appointed to make decisions for a person who requires decision-making support:

- a) The person's will and preferences must be given effect.
- b) Where the person's current will and preferences cannot be determined, the representative must give effect to what the person would likely want, based on all the information available, including by consulting with family members, carers and other significant people in their life.
- c) If it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person's human rights and act in the way least restrictive of those rights.
- d) A representative may override the person's will and preferences only where necessary to prevent harm.³⁴

Alternatives to requiring either consent or decision-making by a parent alone include:

- An approach based on implementing a person's will, preferences and rights
- Where possible, using supported decision-making rather than substitute decision-making
- Changing the setting where decision-making occurs
- Engagement of more diverse expertise in decision-making settings
- Providing formal guidance to health professionals for significant medical intervention decisions

There are different ways to provide settings and advice that can assist families and health professionals to make decisions. Existing approaches could be used to help inform how this might be done in support of a prohibition of deferrable medical interventions. Examples include:

- In the ACT, mental health treatment decisions for people who may lack decision-making capacity are made by the ACT Civil and Administrative Tribunal (ACAT). In cases where the person is a child, the Tribunal is advised by the Chief Psychiatrist and required to take steps to consult with the child, their parents or guardians, and others including carers.
- In Malta, the *Gender Identity, Gender Expression and Sex Characteristics Act 2015* allows exemptions from that country's prohibition of medical modification of the sex characteristics of a child, provided the decisions have been overseen by an interdisciplinary team, and that intervention is not "driven by social factors" (section 14). Thus an interdisciplinary team can authorise interventions, but they would still be illegal if the reason for their agreement was social in nature.
- In Victoria, the *Medical Treatment Planning and Decisions Act 2016* and *Powers of Attorney Act 2014* provide a framework within which "support persons" or "supportive attorneys" can be appointed to support someone who might lack decision-making capacity, to make and communicate decisions about medical treatment. This allows skilled and independent expertise to be brought into decision-making settings.

In addition to these examples, there are other ways in which a range of advisors and expertise could be engaged to support decision-making or monitoring of a prohibition. This could range from formal

³⁴ *Equality, Capacity and Disability in Commonwealth Laws*, ALRC Report 124, recommendation 3 – 3.

supported decision-making requirements, to an oversight committee that includes medical, psychological, legal, human rights and community representation.

Questions:

(16) What decision-making approaches could be effective in ensuring decision-makers, including parents, have sufficient support to make decisions that uphold children's rights and best medical practice?

(17) Should there be an independent or advisory body or person involved in intersex medical intervention decision-making? If an independent body or person plays a role to support decisions around medical interventions on intersex people:

- a) **What should that be?**
- b) **How should it operate?**
- c) **What categories of decisions should be within its remit?**

RESPONDING TO THIS PAPER

The ACT Government would like to hear your expert views and advice in response to any of the questions above. There are other issues that will also need consideration as work on the proposed prohibition progresses. If you wish to provide other feedback, it will also be considered.

Where you argue for or against particular proposals set out in the paper, you are encouraged to supply the best available evidence in support of your suggestions. The same applies in cases where you put proposals in addition to those covered by the paper.

Responses to this draft discussion paper are invited until **5.00PM on 22 January 2021**.

Responses to this paper by email or by phone are welcomed. You can write an email, send a separate note, or you could annotate this paper, and send that in.

If you want to respond by phone, please send an email asking to set up a time to speak.

Please send all emails to: intersex@act.gov.au

This discussion paper has been released under limited circulation. Please contact the Office of LGBTIQ+ Affairs if there are other stakeholders you feel may benefit from reviewing this paper, rather than forwarding it yourself.

NEXT STEPS

The ACT Government will consider all responses to this discussion paper. It will integrate them with literature reviews and research, case studies from other areas of healthcare and other jurisdictions, and advice from intersex people and experts in intersex healthcare. From this, one or more possible options for how a prohibition might work in Canberra will be developed, which will form the basis for further discussion with stakeholders.

Advice for government will then be developed.



Chief Minister, Treasury and Economic
Development Directorate

December 2020