



Australian
Human Rights
Commission
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**Surgery on intersex
infants and human rights**

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1 What is the purpose of this paper?

This paper aims to discuss some of the human rights issues concerning surgeries on intersex infants.

In 2008, the Australian Human Rights Commission (the Commission) undertook a project on human rights and sex and gender diversity. The project included consultation with the sex and gender diverse community about their key human rights concerns. The Commission asked for responses to a short issues paper (see http://humanrights.gov.au/human_rights/gay_lesbian/gender_diversity_paper.html) and held some targeted consultations with sex and gender diverse people. These led the Commission to focus its work for 2008-09 on a project examining the legal recognition of sex on documents and government records (see <http://humanrights.gov.au/genderdiversity/index.html>).

However, many other human rights issues were raised with the Commission during this consultation. One of the issues identified as a priority human rights issue by people who identify as intersex was surgical intervention on intersex infants. As a result, the Commission undertook to raise greater awareness of the human rights implications of this issue.

This paper will cover the following questions:

- 1 What is the purpose of this paper?
- 2 What is intersex?
- 3 Is surgery on intersex infants a human rights issue?
- 4 What human rights issues are particularly relevant to surgery on intersex infants?
- 5 Why is surgery performed on intersex infants?
- 6 What do some advocates seek in relation to surgery on intersex infants?
- 7 What are the benefits and risks of surgery on intersex infants?
- 8 How are the best interests of an intersex infant assessed?
- 9 What protocols exist regarding surgery on intersex infants?
- 10 What work is being done in Australia to look at this issue?
- 11 What are some resources on this issue?

2 What is intersex?

A person who is intersex is a person whose chromosomal, gonadal or anatomical sex is not exclusively 'male' or 'female'. The terms 'hermaphrodite' and 'androgynous' were formerly used to describe some intersex people.

There are many different intersex variations. For some people, genital ambiguity will be obvious at birth. For others, genitalia may appear typically male or female but internal characteristics of sex, such as chromosomes or reproductive organs, are not exclusively male or female.

There is no universal consensus on a broad term to describe all people who are intersex. Historically, the term intersex was used to explain the 'condition' of a person who is born not exclusively male or female. Many medical professionals, and others, now use the term 'disorder of sex development' (DSD) as an umbrella term for a range of different conditions. There are medical terms used to describe particular medical conditions experienced by intersex people, for example Androgen Insensitivity Syndrome (AIS).

Although the term intersex is sometimes used to describe a genetic condition, some people prefer that sex differences, in and of themselves, not be considered a medical condition or a disorder. They use the term intersex as a term of self-identification.

This paper mainly uses the term intersex as a broad term for all people who are not born, or do not develop, as exclusively male or female. While not all these people identify in their lives as intersex – many will identify as either male or female – the term is the least medicalised and most inclusive for the purposes of the paper.

The Commission also uses the phrase 'sex and gender diversity' when referring to variations in sex and gender identity, including when a person has an intersex identity.

3 Is surgery on intersex infants a human rights issue?

People who are intersex have the same human rights as everyone else. Human rights are about respecting the inherent dignity of all human beings.

There is no separate human rights treaty focusing on people who are intersex, but it is clear that all people who are sex and gender diverse have the right to enjoy all the human rights available to other members of the community.

In particular, the fundamental rights of non-discrimination and equality before the law apply to people who are sex and gender diverse. These rights are found in several international human rights treaties, including the *International Covenant on Civil and Political Rights* (ICCPR) and the *Convention on the Rights of the Child* (CRC).

The human rights of children in particular, as set out in the CRC, are especially relevant to the issue of surgery on intersex infants. Some of the key rights include:

- Non-discrimination – all children are entitled to enjoy their human rights without discrimination of any kind (article 2, CRC)
- Best interests – the best interests of the child should be a primary consideration in all actions concerning them (article 3, CRC)
- Development – all children have the right to maximum possible survival and development (article 6, CRC)
- Participation – all children have the right to express their views freely in all matters affecting them, and to have these views given due weight (article 12,

CRC), freedom of expression (article 13, CRC) and freedom of thought, conscience and religion (article 14, CRC)

- Birth registration (article 7, CRC), preservation of identity (article 8, CRC); privacy (article 16, CRC); protection from violence (article 19, CRC), health (article 24, CRC).

The Yogyakarta Principles also confirm that surgery on infants who are intersex is a human rights issue. The Yogyakarta Principles were adopted by a group of international human rights experts in March 2007. The Yogyakarta Principles are not legally binding themselves, but are an interpretation of already binding agreements from the view point of sexual orientation and gender identity. Therefore, the Yogyakarta Principles are persuasive in shaping our understanding of how existing binding human rights obligations relate to people who are sex and gender diverse.

Under the Yogyakarta Principles all international human rights laws, such as the ICCPR and the CRC, apply to people regardless of 'gender identity'.

According to the Yogyakarta Principles, the definition of gender identity is

each person's deeply felt internal and individual experience of gender, which may or may not correspond with the sex assigned at birth, including the personal sense of the body (which may involve, if freely chosen, modification of bodily appearance or function by medical, surgical or other means) and other expressions of gender, including dress, speech and mannerisms (Preamble to Yogyakarta Principles).

This definition protects the right of people who are intersex to choose freely their gender identity. In particular, Principle 18 of the Yogyakarta Principles outlines the right to be protected from medical abuses based on gender identity:

No person may be forced to undergo any form of medical or psychological treatment, procedure, testing, or be confined to a medical facility, based on sexual orientation or gender identity. Notwithstanding any classifications to the contrary, a person's sexual orientation and gender identity are not, in and of themselves, medical conditions and are not to be treated, cured or suppressed.

The Yogyakarta Principles state that countries shall, among other things:

Take all necessary legislative, administrative and other measures to ensure that no child's body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that, in all actions concerning children, the best interests of the child shall be a primary consideration.

4 What human rights issues are particularly relevant to surgery on intersex infants?

As demonstrated by Principle 18 of the Yogyakarta Principles and the CRC, there are several human rights issues relevant to intersex infant surgery. In particular, the child's consent and the best interests of the child are fundamental human rights principles which need to be taken into account when deciding whether to conduct surgery on children.

Consent – who can give consent to surgery on a child?

In Australia, an infant is unable to give consent for surgery. An older child can give consent to surgery when they are at an age where they have sufficient understanding and intelligence to understand what the surgery involves.

A parent or legal guardian can usually consent to surgery when a child is unable to do so. However, a parent should have all the facts to make a decision and must make that decision with regard to a child's best interest (article 3, CRC).

In some circumstances, such as gender reassignment surgery, a parent or guardian cannot give consent for a child to undergo surgical treatment. In these cases, court authority must be sought for the surgery to be performed.

In medical emergencies, consent is not generally required before surgery is performed on a child where it is necessary to save the child's life or prevent serious damage to their health.

The question that arises is whether parents or legal guardians can consent to surgery on an intersex child, when it is not a medical emergency. This issue has not directly been considered in the courts. However, in 1992, the High Court of Australia considered whether a parent could consent to a hysterectomy and ovariectomy to be performed on a 14-year-old child with an intellectual disability. This case is known as Marion's Case.¹ In Marion's Case, the High Court found that court authorisation is required for a medical procedure that:

- requires invasive, irreversible and major surgery, and
- is not for the purpose of curing a malfunction or disease.

The High Court held that authorisation is required because of the significant risk of making the wrong decision concerning a child's best interests and the particularly grave consequences of such a wrong decision.

Although this case concerned a non-therapeutic procedure for a non-intersex child, it is possible, based on Marion's Case, to surmise that court authorisation should be sought before non-therapeutic surgery is performed on an infant who is intersex.

Under the CRC, a child who is capable of forming their own views has the right to express those views in all matters affecting them - including decisions about their health - and for those views to be given due weight. However, this right is to be exercised in accordance with the age and maturity of the child. In situations where surgery is not a medical necessity, it might be more appropriate to delay gender-related surgery until the child is at an age where their views concerning their gender identity and surgery can be taken into account.

Best interests – what is, and who decides what is, in a child's best interest?

Article 3 of the CRC requires that the best interests of the child be a primary consideration in all actions that concern them. Human rights laws do not explicitly

¹ *Department of Health & Community Services v JWB & SMB* (1992), 175 CLR 218 (*Marion's Case*), <http://www.austlii.edu.au/cgi-bin/sinodisp/au/cases/cth/HCA/1992/15.html> (viewed 6 July 2009).

define a child's best interest. It is important to look at the particular circumstances of the child.

However, the CRC is clear on a few points:

- in all actions and decisions affecting an individual child (including those made by medical practitioners), it is the best interests of that individual child which must be taken into account
- parents have primary decision-making responsibility on behalf of their children but the State can intervene if the child's best interests need to be protected.

In order to judge what is a child's best interests it is important to review the various medical and ethical positions concerning surgery on infants who are intersex. Some of the risks and benefits of surgery on infants who are intersex are outlined in section 7.

5 Why is surgery performed on intersex infants?

Surgery is performed on infants who are intersex for two reasons:

- in circumstances where it is a medical emergency or to treat a malfunction or disease (therapeutic surgery), and/or
- to make the body appear more male or female.

In addition to surgery, treatment of children and adults who are intersex can also include hormone replacement therapy.

Historically, intersex conditions were often considered by medical practitioners to be a medical problem that required solving by medical means. Surgery was performed to make a person's body conform with common views about what a male or female body should look like.

In the 1950s, Dr John Money, a psychologist, believed that children are born without a fixed gender identity. According to this view, it was possible to make the genitalia appear male or female and the child could then be raised as a boy or a girl.² Parents and the child were told little about the surgery and treatment to avoid psychological trauma.

One prominent case highlights the problems with the notion that gender can be imposed by raising a child as a boy or girl and providing ongoing hormonal treatment. In the 1960s, an anatomically male infant, David Reimer (also known as Brenda Reimer) was physically reassigned by surgery to look female after a circumcision destroyed his penis.³ David was raised as a girl. By age 13, David had assumed a

² For a discussion of Dr Money's approach to surgery on infants who are intersex, see K J Zucker, 'Gender Identity and Intersexuality' in S E Sytsma (ed) *Ethics and Intersex* (2006), p165.

³ For a discussion of the David Reimer case, see K J Zucker, above, pp 165-181.

male identity. He experienced suicidal depression at 15. David eventually committed suicide.

Although David was not an intersex child, the case indicates that a decision to assign a child a gender identity can have disastrous consequences. It also raises questions about whether a decision to assign a gender identity can be made too early.

6 What do some advocates seek in relation to surgery on intersex infants?

Some adults who are intersex, some medical professionals and some advocates for people who are intersex have challenged the notion that gender can be imposed.

These advocates also scrutinise claims that all surgery on infants who are intersex is medically necessary. While they may recognise that there are occasions when surgery on an infant with a particular intersex condition is therapeutically necessary, these advocates are concerned that non-therapeutic procedures continue to be performed without sufficient attention to the human rights of intersex infants.

There is increasing awareness among medical practitioners and the broader community that several factors can contribute to gender identity and that a particular gender outcome will depend on individual circumstances. Although advances in technology and research allow for a better determination of an individual child's gender, advocates argue that irreversible - and non-therapeutic - gender-related surgery does not always need to occur at birth.

Some advocates are calling for:

- a complete moratorium on all intersex infant surgery that is not therapeutic
- studies that investigate whether the benefits of intersex surgeries outweigh the potential risks
- a greater role for children and young people in consenting to surgery
- a requirement that all surgery on intersex infants that is not therapeutic be approved by a court
- more information to be made available for parents/children about intersex conditions and options other than surgery, to facilitate informed consent.

7 What are the benefits and risks of surgery on intersex infants?

The following list of benefits and risks is compiled from medical literature and information the Commission has received during its consultations. The Commission does not promote any of the benefits or risks but outlines them as potentially relevant considerations in determining the best interests of the child.

See the resources section of this paper for links to medical and other literature which details the surgery which might be performed on a person who is intersex.

Some of the benefits in performing gender-related surgery on intersex infants may include:

- reducing medical risks, such as the greater risk of cancer for some medical conditions, through removal of gonads, or reducing risk of recurrent urinary tract infection
- reducing the risk that the infant will be rejected by parents, discriminated against or ostracised by peers and broader society
- acceptance of the sex and gender assigned at birth by most people who are intersex.

Some of the risks in performing gender-related surgery on infants who are intersex may include:

- the child does not have an opportunity to express their gender identity
- the child may experience psychological damage due to an incorrect imposition of gender
- with certain conditions, infertility being certain, as opposed to probable
- possible complications from surgery, such as haemorrhage.

8 How are the best interests of an intersex infant assessed?

In order to assess what is in a child's best interest in relation to surgery on an infant who is intersex, it is important to weigh up the various risks and benefits of surgery in the case of the individual infant concerned. See section 7 for an outline of some risks and benefits concerning gender related surgery on infants.

Since the decision whether to conduct surgery may have grave consequences for a child's rights, it is important to consider whether surgery is the *only* way that the benefits can be achieved. For example, counselling of parents and greater community education could alleviate the risk that an infant will be rejected or ostracised.

Decisions concerning a child's best interests require consideration of current medical research and investigation about whether gender related surgeries are undertaken for medical risks or psycho-social reasons.

Some advocates argue that decisions concerning gender related surgery on infants are so important that decisions, at least for non-life threatening conditions, should be made by courts that are able to take a more objective perspective in determining a child's best interests. This is currently the case with some non-therapeutic surgeries.

There are also practical considerations to be taken into account with requiring court authorisation, such as how to reduce the stress and difficulties of court proceedings for parents.

9 What protocols exist regarding surgery on intersex infants?

In 2006, a multi-disciplinary and international group of medical experts developed a consensus statement on the management of disorders in sex development (DSD) (see below). A DSD includes a person who is intersex. Parents of children with a DSDs and adults with DSDs were also involved in developing the consensus

statement. The consensus statement advocates that surgery be performed on infants after an evidence-based decision is made about the child's likely gender.⁴

10 What work is being done in Australia to look at this issue?

Government, medical professionals and human rights advocates are interested in addressing some of the issues concerning surgery on infants who are intersex.

In Tasmania, the Department of Health and Human Services is actively considering the various issues concerning surgery on infants who are intersex. In addition to meeting with clinicians and specialists to identify current practice, the Department of Health and Human Services is seeking to establish an informal intersex reference group to identify and/or draft resources and reference materials that may be of assistance to the families of intersex babies as well as health and community professionals. For more information contact the Population Health Unit at the Tasmanian Department of Health and Human Services.

The Tasmanian Children's Commissioner has considered the issue of surgery on infants who are intersex in light of a child's right to genital autonomy. The Tasmanian Children's Commissioner has information on different aspects of genital autonomy on its website and in 2008 attended the Tenth International Symposium on Circumcision, Genital Integrity and Human Rights. For more information see the Tasmanian Children's Commissioner's website at <http://www.childcomm.tas.gov.au>.

In Victoria, the Ministerial Advisory Committee on Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) Health and Wellbeing and the Attorney-General's Advisory Committee on GLBTI issues are collaborating on a review of surgery on infants who are intersex. For more information contact the Victorian Diversity Unit at the Department of Human Services.

In addition, several Australian clinicians are involved in developing universally applicable principles to guide decision-making in relation to infants who are intersex. The principles include:

- minimising physical risk to a child
- minimising psycho-social risk to a child
- preserving potential for fertility
- preserving or promoting capacity to have satisfying sexual relations
- respect parents' values and wishes
- leaving options open for the future.

For more information contact Dr Jacky Hewitt at the Murdoch Children's Research Institute, Royal Children's Hospital Melbourne on (03) 8341 6426 or jacky.hewitt@rch.org.

⁴ For more information on the consensus statement, see www.dsdguidelines.org/.

11 What are some resources on this issue?

Human rights guidelines

The Yogyakarta Principles – <http://www.yogyakartaprinciples.org/>

Medical Guidelines

Disorders of Sex Development guidelines - www.dsdguideliness.org/

Information for parents

Information for parents on disorders of sex development – www.dsdguideliness.org/

A guide for parents of children born with ambiguous genitalia - <http://home.vicnet.net.au/~aissg/Ambiguous%20Genitalia%20Parents%20Guide.pdf>

Intersex Society of North America

Legal papers

J A Grennberg, 'International Legal Developments Protecting the Autonomy Rights of Sexual Minorities' in S E Sytsma (ed) *Ethics and Intersex* (2006), p 87.

K J Zucker, 'Gender Identity and Intersexuality' in S E Sytsma (ed) *Ethics and Intersex* (2006), p 165.

A C Lareau, 'Who decides? Genital-Normalizing Surgery on Intersex Infants' (2003 Nov) 92(1), *Georgetown Law Journal*, p 129.

K Parlett and K Weston-Scheuber, 'Consent to treatment for transgender and intersex children' (2004) 9(2) *Deakin Law Review*, p 375.