

AMNESTY INTERNATIONAL POLICY STATEMENT ON THE RIGHTS OF INTERSEX INDIVIDUALS

INTRODUCTION

Amnesty International's policy on the rights of intersex individuals seeks to ensure that intersex individuals are guaranteed the full exercise and enjoyment of all human rights. It also seeks to respond to the suffering caused by abuses of these rights.

WHAT DOES INTERSEX MEAN?

Intersex individuals possess genital, chromosomal or hormonal characteristics which do not correspond to the given standard for 'male' or 'female' categories of sexual or reproductive anatomy. Intersexuality may take different forms and cover a wide range of embodiments.¹ Intersexuality can also be a way of naming sexed bodily diversity.

KEY ISSUES

A person's 'intersex' status may be diagnosed at birth, at puberty, when attempting to conceive a child, or even at autopsy. It should be noted that intersexuality is not always diagnosed as such. Doctors, other health professionals will often simply say that a child has abnormally large, small or 'ambiguous' genitalia.² Infants and children with genitalia that is not easily classifiable as 'male' or 'female' often undergo genital surgery or pharmaceutical procedures to 'correct' their genital presentation and are then 'assigned' a corresponding male or female gender.³ Often, multiple surgeries are performed followed by hormone treatment to 'fix' the child in his or her assigned gender. This is usually prescribed by medical professionals with the consent of parents or guardians. The surgery and the early gender assignment can result in serious emotional and physical trauma to the individual, and often results in significantly reducing sexual sensitivity. It can also very often result in the loss of fertility, and can in some cases cause urinary tract problems. Many intersex individuals assigned a particular gender in infancy often later realize that they do not identify with the sex and gender they were assigned.⁴

Surgical treatment of genital abnormalities began as an 'innovative' treatment: one which "has not been tested sufficiently to meet the standard of having a 'reasonable expectation of success'".⁵ Surgery performed on children who are unable to consent, or on adults who give their consent without full and thorough consultation, may violate the right to protection from medical abuses. This is especially the case when treatments are performed for no medical purpose, but purely to make the individual conform to standard categories of 'male' or 'female'.

1 Discrimination on grounds of sexual orientation and gender identity in Europe, Council of Europe, June 2011, p.131. Definition of 'intersex' from World Health Organization, "Genetic components of Sex and Gender". See also Federal Anti-Discrimination Agency, Benachteiligung von Trans Personen, insbesondere im Arbeitsleben, Berlin, 2010, p. 11.

2 In the US, approximately 1 in 2000 infants are born with ambiguous genitalia. Beh and Diamond, 'An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment on Infants with Ambiguous Genitalia?', Michigan Journal of Gender & Law, Volume 7(1): 1-63, 2000. Copy available: <http://www2.hu-berlin.de/sexology/BIB/DIAM/dilemma.htm>

3 Approximately 100-200 paediatric surgical sex reassignments are performed in the US each year. Beh and Diamond, 2000

4 Chavez, C., 'Intersex', Gender Equity Resource Centre, University of California, Berkeley, 2008.

5 Beh and Diamond, 2000

In fact, the primary outcome of surgical treatment is to alleviate parental discomfort; it is a surgical treatment for a psychosocial condition. Non-surgical approaches (individual and family counselling) could address this without closing off future options.⁶ There is a consistent and growing body of evidence that children raised with “ambiguous” sex anatomy are at no greater risk for psychosocial problems than the general population, and little published evidence to the contrary.⁷ Emerging guidelines advocate delaying elective surgeries until the patients themselves can participate in decision-making.⁸

A report prepared by the San Francisco Human Rights Commission found that no evidence indicates that intersex children benefit from “normalizing” interventions. Existing data suggest that the long-term consequences of “normalizing” genital surgeries are quite negative. There is little positive follow-up data from patients who have been subjected to clitorectomies or clitoroplasties during the last ten years. Specifically, there are no data that reflect patient satisfaction with the surgical outcome, suggest that the reconstructed genitals are structurally and functionally “normal,” or indicate quality of life has been improved.⁹

Critics of infant surgeries argue that ambiguous genitalia is not an urgent problem that needs to be fixed.¹⁰ All genital surgeries performed on children are also available to young adults when they are able to give informed consent themselves. Moreover, better medical results are expected on a larger anatomy.¹¹

Diamond and Sigmundson (1997) recommend that children with intersex conditions, and their parents, be given support so that they come to understand that the condition is “normal although atypical”.¹² They advocate “full and honest disclosure” while maintaining confidentiality, and rearing the child according to the most likely outcome: this is defined by “how the child will develop and prefer to live post puberty when he or she becomes most sexually active”.¹³ Most importantly, they advocate postponing surgery, and prolonged hormone administration (when not medically necessary) until after puberty, or until the patient is able to give informed consent.¹⁴ Laurence McCullough (1999) recommends that “in balancing the desirability of normal-appearing genitalia with the foreclosure of the child’s ability to later consent, the scales tip in favour of delaying treatment.”¹⁵

6 Beh and Diamond, 2000

7 http://www.accordalliance.org/dsdguidelines/htdocs/clinical/timing_of_surgeries.html

8 http://www.accordalliance.org/dsdguidelines/htdocs/clinical/timing_of_surgeries.html

9 San Francisco Human Rights Commission, “A Human Rights Investigation into the Medical “Normalization” of Intersex People: A Report of a Public Hearing by the Human Rights Commission of the City & County of San Francisco”, 2005, available from: http://www.isna.org/files/SFHRC_Intersex_Report.pdf

10 Beh and Diamond, 2000

11 San Francisco Human Rights Commission, “A Human Rights Investigation into the Medical “Normalization” of Intersex People: A Report of a Public Hearing by the Human Rights Commission of the City & County of San Francisco”, 2005, available from: http://www.isna.org/files/SFHRC_Intersex_Report.pdf

12 Diamond and Sigmundson, ‘Management of Intersexuality: Guidelines for dealing with individuals with ambiguous genitalia’, Archives of Pediatrics and Adolescent Medicine, Volume 151: Pages 1046-1050, 1997, available from: <http://www.isna.org/library/ManagementofIntersex.pdf>

13 Diamond and Sigmundson, 1997

14 Diamond and Sigmundson, 1997

15 According to Diamond and Sigmundson, 1997

Diamond and Sigmundson also acknowledge that there are intersex individuals who have “had early surgery of one sort or another, or even sex reassignment, and gone on to be happy and lead successful lives”, but advocate the use of their guidelines as “an attempt to consider ways to better life and adjustment for those intersexed and genitally traumatised persons still battling with these issues and for those yet to come.”¹⁶

It should be noted that many intersex individuals reject the medicalisation of their identities and the diagnoses of their bodies. For many, ‘intersex’ is a political and personal identity rather than a medicalised ‘condition’. There are a raft of human rights concerns that lie beyond the medicalisation of intersex bodies and identities. Even where intersex individuals have not undergone ‘normalising’ or ‘corrective’ medical procedures, as adults or as children, the very fact of possessing an intersex body can, in some cases, lead to discrimination, exclusion and violence. Greater awareness needs to be created about bodily diversity, and medical professionals and institutions should proffer such information to parents and guardians of children whose sexual and reproductive bodies fall outside of the conventional male/female binary.

RIGHTS VIOLATED

The performance of surgical or pharmaceutical procedures on children must respect the principle of the best interest of the child in all cases. Surgeries or pharmaceutical procedures should not be used to impose standard categories of ‘male’ or ‘female’ on children based on the desires of parents and health professionals for the child to be ‘normal’. Furthermore, the best interests of the child principle¹⁷ should never be used to justify unwanted and invasive medical procedures based on the desire of parents or guardians to make their child conform to gender norms. Ideally, intersex individuals need to be able to exercise informed consent to such procedures. In general, intersexuality is not a medical emergency calling for surgical intervention, save in exceptional cases. Where surgery is considered necessary, this needs to be based on the best available and ethical medical research which is also endorsed by intersex groups. Assigning a gender to children through irreversible surgery or pharmaceutical treatments, when there is no immediate medical necessity, violates the best interest of the child principle.

Intersex individuals may also experience violations of their right to health when seeking healthcare, as a result of health professionals’ prejudice, fear or lack of knowledge about healthcare requirements for intersex people.

Intersex individuals are also vulnerable to violations of their right to freedom from discrimination in all spheres of life. Individuals whose appearance, gender expression or gender identity do not match the gender markers on official documents risk having their right to privacy violated whenever they are required to prove their identity. They are also at risk of violations of their economic, social and cultural rights through discrimination in employment, education and housing.

When intersex people who wish to correct the gender they were forced into adopting are legally and medically treated as transgender individuals under the health system, another set of discriminatory conditions can apply in addition to the ones mentioned here. See Amnesty International policy paper on transgender issues.

AMNESTY INTERNATIONAL’S POSITION

Amnesty International calls on States to:

Ensure the rights of intersex individuals to appropriate healthcare and medical treatment

¹⁶ Diamond and Sigmundson, 1997

¹⁷ Article 3 of the Convention on the Rights of the Child: 1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

- Ensure that medical procedures performed on intersex infants and children are premised on the best interests of the child, and do not impose standard categories of 'male' or 'female' on children based on the wishes of parents, guardians and health professionals for their child to be 'normal'. Where possible, any surgical procedures should be postponed until intersex individuals are able to exercise informed consent to such procedures. When dealing with medically indexed exceptional cases, any surgical intervention must be based upon the best available and ethical medical research which is also endorsed by intersex groups.
- Ensure that intersex adults are able to give informed consent to procedures performed on them.
- Ensure that intersex adult individuals have access to surgical or hormonal treatment if they wish to undergo such treatment, without undue burdens of cost or time.
- Ensure that intersex individuals have access to the highest attainable standard of health, and that state and private medical facilities do not discriminate on the grounds of gender identity.
- Ensure that intersex individuals do not have their reproductive rights violated, in the form of sterilisation or any other form of medical treatment.
- Ensure intersex persons' ability to access to all medical records.
- Ensure that parents and guardians have the right to access unbiased information about bodily diversity from medical professionals and institutions.

End discrimination against intersex individuals

- Ensure that all anti-discrimination legislation specifically includes the prohibition of discrimination on the grounds of gender identity and/or expression.
- Monitor existing legislation, policies and other measures to ensure that the right not to be discriminated against on the grounds of gender identity is protected.
- Ensure that human rights defenders working to promote the human rights of intersex individuals are protected.

Ensure the right of intersex individuals to recognition before the law

- Allow individuals who identify as a gender that is neither male nor female to obtain official papers which reflect their gender identity.
- Ensure that individuals are able to obtain official documents provided by other institutions, such as certificates of education, that reflect their gender identity, without undue cost or time burdens.
- Ensure that individuals who were assigned to a sex at birth that does not reflect their gender identity are able to obtain documentation that reflects their gender identity.
- Ensure that parents are given sufficient time to declare and/or change the gender marker of their infant when the child is intersex.

Ensure the right to privacy for intersex individuals

- Ensure that the process for issuing documentation reflecting an individual's gender identity respects their right to privacy.

End discrimination on grounds of gender identity within the criminal justice system

- Repeal all laws that criminalise particular gender identities and expressions, including but not

limited to laws against cross-dressing, gender reassignment and same-sex behaviour. Same-sex acts are included here as in some countries intersex individuals are targeted and prosecuted by the State under laws that criminalise same-sex acts, even when intersex individuals are heterosexual.

- Ensure that security forces do not use existing laws to target intersex individuals for harassment or imprisonment.
- Ensure that intersex individuals are placed in facilities appropriate for their gender identity, and that they are not further marginalised while in detention, for example by being detained in solitary confinement, or placed with detainees where violence is a high probability.
- Ensure that state actors who violate the human rights of intersex people are held legally accountable, and that the victims of such violations are able to seek appropriate reparations.
- Access to proper health care must be granted to intersex people in detention.

Ensure the rights of intersex individuals to found a family

- Ensure that intersex individuals are able to enjoy marriage and partnership rights.
- Ensure that an intersex individual's gender identity and/or gender expression does not affect their assessment as a suitable adoptive parent or their custody rights.
- Ensure that an intersex individual's gender identity/and or gender identity does not prevent them from accessing assisted reproductive technology, where needed.
- Ensure that immigration and asylum laws and policies do not prevent family reunification as a result of discrimination on the grounds of gender identity or gender expression.

Protect the right to life of intersex individuals

- Ensure that non-state actors who violate the human rights of intersex people are held accountable, and that the victims of such violations are able to seek appropriate reparations.
- Ensure that Immigration departments or ministries recognise as real the risk of harassment and persecution on the grounds of gender identity or gender expression when considering asylum applications made by intersex people.

Ensure the economic, social and cultural rights of intersex people

- Ensure that intersex individuals are not discriminated against in employment, education or housing.
- Ensure the rights to freedom of expression, association and participation in political and cultural life for intersex people.

RESPONSIBILITIES OF OTHER ACTORS

Amnesty International calls on health professionals to create standards for the treatment of intersex children that are demonstrably based on the best interest of the child and best available medical and ethical research. In addition, they must act in accordance with principles of international human rights and medical ethics when providing services to intersex individuals. They must ensure respectful professional conduct that promotes the dignity of every individual without discrimination on any grounds, and must respect individuals' right to autonomy, privacy, confidentiality, informed consent or dissent and choice.

DEFINITIONS

Intersex individuals possess genital, chromosomal or hormonal characteristics which do not correspond to the given standard for 'male' or 'female' categories as for sexual or reproductive anatomy. Intersexuality may take different forms and cover a wide range of conditions.¹⁸

Gender identity refers to 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.¹⁹ An individual's gender identity may be male, female, or a gender which is neither male nor female; it may also be more than one gender, or no gender.

Gender expression refers to the means by which individuals express their gender identity. This may or may not include dress, make-up, speech, mannerisms, surgical or hormonal treatment.²⁰

18 Discrimination on grounds of sexual orientation and gender identity in Europe, Council of Europe, June 2011, p.131. Definition of 'intersex' from World Health Organization, "Genetic components of Sex and Gender". See also Federal Anti-Discrimination Agency, Benachteiligung von Trans Personen, insbesondere im Arbeitsleben, Berlin, 2010, p. 11.

19 http://www.yogyakartaprinciples.org/principles_en.htm .

20 An Activist's Guide to the Yogyakarta Principles, August 2010, p.24.