Human Rights Violations Against Intersex People

A Background Note
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Introduction and methodology
“Intersex” is an umbrella term used to describe a wide range of innate bodily variations in sex characteristics. “Intersex” people are born with sex characteristics that do not fit typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns.

In recent years, awareness of intersex people, and recognition of the specific human rights abuses that they face, has grown, thanks to the work of intersex human rights defenders. These include risks of forced and coercive medical interventions, harmful practices and other forms of stigmatisation due to their physical traits. To date, only a handful of countries have implemented measures to prevent and address such abuses, and the effectiveness of existing measures remains to be fully documented.

In response, the United Nations Human Rights Office has undertaken a series of activities to raise public awareness of intersex human rights issues and deepen understanding of relevant international human rights law standards and recommendations and how they apply to the situation of intersex people. In September 2015, the United Nations Free and Equal campaign released a first fact-sheet on the rights of intersex people. In the same month, UN and regional human rights mandate holders, intersex experts, UN agency staff, experts from national institutions and academia, civil society representatives and health professionals convened for the first UN Expert Meeting on ending human rights violations against intersex persons (see appendix 11.1). In October 2016, in part as a follow up to the Expert Meeting, a joint call by United Nations and regional human rights experts was published (see appendix 11.2), calling on Governments to prohibit forced and coercive surgeries and other medically unnecessary treatments on intersex children without their consent. The United Nations Human Rights Office also launched the first UN public education campaign on the rights of intersex people, United Nations for Intersex Awareness, with a dedicated website and a video watched by more than a million people in its first week of release.

This Background Note complements and builds on these initiatives, documenting the specific human rights abuses faced by intersex people and the corresponding human rights obligations of States, identifying gaps, challenges and positive developments, and charting the way forward to ensure that the human rights of intersex people are respected, protected and fulfilled.

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Understanding intersex
Intersex is an umbrella term used to describe a wide range of innate bodily variations of sex characteristics. According to experts, between 0.05 per cent and 1.7 per cent of the population is born with intersex traits.4

**WHO ARE INTERSEX PEOPLE?**

Intersex people are born with physical sex characteristics (such as sexual anatomy, reproductive organs, hormonal patterns and/or chromosomal patterns) that do not fit typical definitions for male or female bodies.

Intersex people have many different kinds of characteristics or traits. These traits may be evident prenatally or at birth, they may emerge at puberty, or become apparent later in life.

Intersex people are subjected to human rights violations because of their physical characteristics. Intersex children and adults are often stigmatized and subjected to multiple human rights violations, including violations of their rights to be free from torture and ill-treatment, to health and physical integrity, and to equality and non-discrimination.

Human rights violations include forced and coercive medical interventions; infanticide; restrictions on the exercise of legal capacity and in access to remedies and justice; discrimination in access to education, sport, employment and services. The root causes of human rights violations against intersex people include harmful stereotypes, stigma, taboos, and pathologization (i.e. treating intersex persons as necessarily ill or disordered).

**TERMINOLOGY**

Intersex people use many different terms to describe themselves, their bodies, sex characteristics and identities. Some people consider themselves to be intersex, while others consider themselves individuals who have an “intersex variation”, an “intersex trait”, or are “born with a variation of sex characteristics”. Other terms such as “intersex condition”, and “differences of sex development” (abbreviated as DSD) are sometimes used, though some consider these terms to be medicalized.

Intersex persons, their parents and medical practitioners may make use of diagnostic terms. These change over time reflecting, in part, a shift from terms based on gonadal tissue5 and observation, towards terms based on genetic information. In medical settings, the term “disorders of sex development” (also abbreviated as DSD) is frequently used by medical professionals and institutions, as well as by some parents of intersex persons and some intersex persons themselves. The term is widely rejected by many intersex people and human rights defenders as pathologizing, stigmatizing and as encouraging medically unnecessary interventions to modify the sex characteristics of intersex persons.6

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5 i.e., ovaries, testes and ovotestes.

Historical terms include “hermaphrodite”. This term has an ancient history associated with religious and civil jurisprudence that recognizes a diversity of intersex bodies, and facilitates marriage, inheritance and ordination depending on individuals’ predominant characteristics.7 However, such old terms are often now considered pejorative by many intersex persons. In particular, the term hermaphrodite has taken on a narrow meaning in biological science8 and so it can promote misleading and homogenizing ideas about the appearance and capabilities of intersex bodies. Some other intersex people use and reclaim the term.

It is important to always respect people’s choice of terms to refer to themselves.

CONTEXTUALIZING THE RIGHTS OF INTERSEX PEOPLE

Human rights issues affecting intersex people share common features with human rights issues affecting other vulnerable populations, with the effect that multiple UN Treaties and frameworks are relevant to the situation of intersex people.

Intersex people are born with sex characteristics that vary from norms for female and male bodies. Because of this, intersex people are frequently subjected to so-called “normalizing” procedures to make them conform to sex and gender stereotypes. These include ideas that women must be able to have vaginal intercourse and men must be able to stand to urinate, and the idea that bodies need to be modified to make them socially acceptable. Gender stereotypes, including play and other behavioural preferences, can be used as rationales for medical interventions.9

Sexual health is understood as a state of physical, emotional, mental and social well-being in relation to sexuality that encompasses reproductive health – including being able to control one’s fertility, being free from sexual dysfunction, being free from sexual violence and female genital mutilation (and their consequences) having the freedom to decide what happens to one’s own body, including the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.10

Sexual health and other rights may be violated due to stigma, institutional violence and forced medical interventions throughout intersex people’s lifetimes.11 Harmful practices on intersex children – whether in medical or other settings – have lifelong consequences for physical and psychological health.

Parents of intersex children may be pressured into agreeing to “normalizing” and unnecessary medical interventions in order to obtain identification documents for their children.12 Unnecessary medical interventions may take place deliberately before children are old enough to understand the nature of a

procedure. In some jurisdictions, specific legal sex classifications may be designed for intersex children, singling them out for special attention and with deleterious consequences.\textsuperscript{13}

The stigmatization of intersex bodies shares many commonalities with stigmatization faced by persons with disabilities. This is due to the historical dominance of the medical model of disability which seeks to “cure” or “correct” children and adults with disabilities. In this respect, both intersex people and persons with disabilities face forced and coercive medical interventions, sterilization and discrimination based on physical and genetic differences. Both groups are considered to be unhealthy on the basis that they do not conform to social and medical norms. Pregnant women may receive biased advice during pregnancy and efforts should be made to ensure elimination of discriminatory attitudes and prejudices, while also upholding women’s autonomy to make decisions about their lives and bodies, and sexual and reproductive health and rights. There are also overlaps between both populations as intersex individuals may have chronic conditions or impairments due either to their innate characteristics or as a consequence of medically unnecessary surgery and other treatment performed on them without their informed consent.

Many intersex organizations and experts have highlighted the relevance and applicability of the social model of disability to intersex people, which focuses on barriers within society as the source of disadvantage and discrimination, rather than on an individual’s particular characteristics.\textsuperscript{14} A national inquiry in Australia in 2012–3 has recognized common experiences faced by persons with disabilities and intersex people,\textsuperscript{15} and the German Institute for Human Rights has utilized the CRPD framework in relation to intersex people, as have disability representative organizations in Australia.\textsuperscript{16} Some intersex organizations have expressed caution about positioning intersex issues mainly or solely within the framework of the rights of persons with disabilities, including fears about exacerbating stigma faced by intersex people.\textsuperscript{17}

Intersex people share some common concerns with lesbian, gay, bisexual and transgender (LGBT) people due to shared experiences of harm arising from dominant societal sex and gender norms.\textsuperscript{18} Human rights violations affecting intersex people may take place before they are able to develop or freely express an identity,\textsuperscript{19} but stereotypes, fear and stigmatization of LGBT people provide rationales for forced and coercive medical interventions on children with intersex variations. Intersex people have


\textsuperscript{17} OII Europe, “Statement of OII Europe on Intersex, Disability and the UN Convention on the Rights of People with Disabilities”, n 14.


diverse sexual orientations and gender identities, and so intersex and LGBT populations overlap. Some intersex persons may identify with the sex marker assigned at birth, while others may not. Some may feel forced into legal sex and gender categories that they do not identify with, including binary (male or female) and third or non-binary categories. Potential future LGBT identities in intersex children are frequently ignored by clinicians or presented as adverse outcomes, and intersex people who are lesbian, gay, bisexual or transgender may face additional burdens of discrimination.

At the same time, intersex persons have distinct lived experiences and human rights concerns. Attempts to include intersex within a framework around “sexual orientation and gender identity” (SOGI) have frequently lacked relevance or specific consideration of human rights issues affecting intersex persons. As a result, a number of civil society organizations and human rights experts and institutions have expanded that framework to add issues relating to “sex characteristics” – notably in the recently updated Yogyakarta Principles plus 10.

Some intersex advocates and organizations have identified concerns regarding representation, misrepresentation and resourcing, and the extrapolation of data and policy frameworks on LGBT populations to an intersex population without clear evidence supporting that inclusion. Intersex-led and other organizations have expressed fears that this exacerbates stigma faced by intersex people. Kenyan research has found that the conflation of intersex with LGBT issues contributed to stigma and also impaired “an intersex person’s ability to receive a fair trial in a court of law”. At the same time, a report on legal gender recognition in the Asia-Pacific region states that culturally-specific conflations of terms for intersex and transgender people “obscure the specific experiences and distinct human rights issues affecting each group”. Some intersex organizations prefer to organize independently or align themselves with other movements.

Intersex human rights defenders call for the specific resourcing and leadership of intersex-led organizations. At the United Nations, the Office of the High Commissioner for Human Rights has highlighted the importance of a focus on specific human rights violations faced by intersex people.

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20 An intersex person may be female, male, both, neither, or non-binary, and may be heterosexual, gay, lesbian, bisexual or asexual.
26 Davis et al, n 18; Koyama and Weasel, n 24.
GROUNDS FOR DISCRIMINATION

In recent years, different legal grounds have been used to address human rights violations faced by intersex people and protect them from discrimination.

South Africa added protections for intersex people within existing protections from discrimination on grounds of sex, in 2005.30 In 2013, Australia enacted explicit protections from discrimination on grounds of intersex status.31 The Inter-American Commission on Human Rights considers violence and discrimination against intersex persons as violence and discrimination on the ground of bodily diversity.32

In 2015, Malta enacted legislation that protects all people, including intersex people, from discrimination and forced and coercive medical interventions on grounds of sex characteristics. This ground has since been adopted by multiple international institutions, including the Asia Pacific Forum of National Human Rights Institutions in 2016, and the European Parliament in 2019.33 The 2017 Yogyakarta Principles plus 10 define sex characteristics 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”.34

UN bodies have taken a diversity of approaches, including attempts to address discrimination against intersex people within the framework of sexual orientation and gender identity. The attribute of “sex characteristics” is now an emerging standard.

PROMOTING THE RIGHTS OF INTERSEX PEOPLE

The human rights of intersex people have historically been poorly addressed, perhaps due to societal taboos, and lack of public awareness, stigmatization, a lack of transparency about clinical practices, resistance to human rights norms in medical settings, and misconceptions. As a result, intersex people remain largely invisible. Awareness of the existence and rights of intersex people within human rights frameworks is growing thanks to the work of intersex human rights defenders in a largely volunteer-run movement.35

States have an obligation to tackle human rights violations against intersex people and their root causes. Only a handful of countries have so far taken concrete measures to uphold the rights of intersex people and protect them from abuses. Even in countries that have taken positive steps, there is a gap between legislation and policy, on the one hand, and the lived realities of intersex people, on the other.

31 Australia. Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013.
This requires urgent action by States, national human rights institutions, United Nations and regional entities, civil society and other stakeholders.36

**UNITED NATIONS EXPERT MEETING**

The Office of the United Nations High Commissioner for Human Rights convened a first expert meeting on ending human rights violations against intersex persons in September 2015.

In his opening remarks, then High Commissioner Zeid Ra’ad Al Hussein highlighted the seriousness of human rights violations faced by intersex people, combined with the stigma and taboo attached to being intersex, lack of investigation and prosecution of violations, impunity for perpetrators, absence of remedy, and a cycle of ignorance and abuse.

Experts unpacked different human rights standards, noting the applicability of multiple and complementary human rights frameworks, including those relating to torture and cruel, degrading and inhuman treatment; the rights of the child, of women, and of persons with disabilities; harmful practices including female genital mutilation (FGM);37 violations of physical and mental integrity, autonomy, free and informed consent; and discrimination.

Experts examined factors influencing forced and coercive medical practices, including surgeries, such as stigma and discriminatory prejudices or beliefs, heightened vulnerability and a generalized lack of a human rights approach within medical settings, absence of safeguards training on respecting fundamental human rights in healthcare, to nomenclature and medical classifications relating to intersex persons. Experts noted the continuous nature of harm, with lifelong health consequences and deep impacts on life trajectories.

Experts reflected on some limited positive developments but noted that, in most places, these have not yet translated into significant or widespread evidenced improvements in protections of the rights of intersex people, nor in access to remedies.

Following the expert meeting, a number of United Nations treaty bodies, special procedures and regional human rights bodies adopted a joint statement calling for States to urgently adopt measures to end violence and harmful practices against intersex people.38

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36 Office of the High Commissioner for Human Rights, n 33; Monro et al, n 11.
37 Joint CEDAW/CRC General Comment 31/18 on Harmful Practices
38 Public statement of UN and regional human rights experts, n 2.
Forced and coercive medical interventions
• Forced and coercive medical interventions violate rights to the security of person, right to bodily and mental integrity, freedom from torture and ill-treatment, and freedom from violence. The right to security of the person, including freedom from injury to the body and the mind, or bodily and mental integrity is protected by the first substantive right in the Universal Declaration of Human Rights, article 3, as well as article 9 of the International Covenant on Civil and Political Rights, and article 17 of the Convention on the Rights of Persons with Disabilities.

• Forced and coercive medical interventions violate a right to health (including a right to free and informed consent), a right to legal capacity, and a right to non-discrimination. The right to health includes the right to control one’s health and body, including sexual and reproductive rights, freedom from interference, and the right to be free from torture, non-consensual medical intervention and experimentation.

• All people have the right to privacy, including the right to private life, freedom from arbitrary or unlawful interference with privacy, and a right to the development and preservation of identity.

• States have a legal obligation to protect all children from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation. Children have the right to freedom from violence, and freedom from torture and ill-treatment.

• When medical procedures take place without personal informed consent, they violate the right to freedom from experimentation.

• Poor, inadequate or partial information regarding the nature of a diagnosis, procedure or long-term outcomes, or the availability of peer support, violate the right to health and the right to accessible information and to free and informed consent.

• States must take measures to abolish harmful practices and other traditional practices prejudicial to children’s health, including through rights-based strategies that adequately sanction or criminalize harmful practices, combat impunity and provide redress for victims.

• The Committee on the Rights of the Child has cautioned that the requirement to give priority to the “best interests of the child” may be open to manipulation and should not be abused to justify discriminatory policies. The Committee has stated that assessments of a child’s best interests must

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39 Committee on Civil and Political Rights, “General Comment No. 35: Article 9 (Liberty and Security of Person)” (CCPR/C/GC/35, 16 December 2014) at 2 to 3, and 9; Yogyakarta Principles, n 25, p 10.


49 Committee on the Rights of the Child, “General Comment No. 14 (2013) on the Right of the Child to Have His or Her Best Interests Taken as a Primary Consideration (Art. 3, Para. 1)” (CRC/C/GC/14, 29 May 2013) at 34.
encompass the views of the child, and interpretations of a child’s best interests cannot be used to justify practices that conflict with human dignity and the right to physical integrity.50

• States’ obligation to eliminate forced, coercive, and unnecessary medical interventions to modify variations of sex characteristics, and violence against intersex persons includes investigating, prosecuting alleged perpetrators, providing victims with remedy, addressing patterns of violence, and tackling root causes.

• In order to prevent human rights violations, and linked with the right to health, states should develop and implement human rights-based health-care protocols for intersex children.51

In countries around the world, intersex infants, children and adolescents are subjected to medically unnecessary surgeries, hormonal treatment and other procedures in an attempt to forcibly modify their appearance or physical development to be in line with societal expectations about female and male bodies.52 As one intersex expert notes:

Forced and coercive medically unnecessary interventions on the bodies of intersex children may sometimes be described critically or euphemistically as “normalization” surgeries, but also as “corrections,” treatment for “malformations,” genital “enhancement,” “genital reconstruction,” “sex assignment” or “gender assignment,” or “gender reassignment.” The procedures involved may include labiaplasties, vaginoplasties, clitoral “recession” and other forms of clitoral cutting or removal, gonadectomies, hypospadias “repairs,” phaloplasties and other forms of penile augmentation surgeries, other forms of urogenital surgeries, and prenatal and postnatal hormone treatment. Associated practices may include dilation, repeated genital examinations, post-surgical sensitivity testing, and medical photography.53

There is no clinical consensus about surgical timing, indications, necessity, procedure or outcome evaluation, and the quality of supporting clinical evidence is low.54 These procedures violate the rights of persons subjected to such procedures when they occur without their full, free and informed consent.55 When non-urgent interventions are invasive or irreversible, they are associated with high potential for, and evidence of, harm. These interventions can be distinguished from medical interventions essential for physical health, such as when an infant is unable to urinate, or unable to retain salt.

Testimonies have documented profound negative impacts of these often irreversible procedures, including permanent infertility/sterilization, incontinence, loss of sexual function and sensation, and experiences tantamount to rape (such as dilation, the repeated insertion of a device into a newly opened vaginal cavity), causing life-long pain and severe psychological suffering, including depression.
and shame linked to attempts to hide and erase intersex traits. In 2013, Juan Méndez, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment remarked that such interventions result in “permanent, irreversible infertility and causing severe mental suffering”. In 2018, Catalina Devandas-Aguilar, Special Rapporteur on the rights of persons with disabilities, remarked that there “are a growing number of treatments and interventions whose effectiveness is uncertain or deemed controversial” which “are invasive, painful and irreversible, and therefore may amount to torture or ill-treatment if applied involuntarily”.

Intersex organizations have highlighted concerns that children are frequently subjected not to one but an ongoing series of surgeries, treatments, follow-up treatments, and treatments to address complications that frequently arise, all of which are reported as painful and deeply traumatising by many intersex persons who have undergone them. In addition, repeated genital exams, photography and exposure, including in the context of training other medical professionals, have been experienced as deeply shaming, traumatic, and been described as a form of sexual abuse.

In many cases the medical histories of intersex people have been concealed from them, or they have been denied access to their own medical records. The Office of the Privacy Commissioner in New Zealand and the Kenya National Commission on Human Rights have identified variable progress in changing this clinical paradigm.

STERILIZATION, FERTILITY, AND SEXUAL AND REPRODUCTIVE RIGHTS

Forced or coercive sterilizations violate the sexual and reproductive rights of intersex people. As with people with disabilities, laws protecting people from involuntary or coerced sterilization may not be enforced in relation to intersex people. Sterilization may occur as a by-product of medical interventions justified on the basis of potential risks of cancer as well as by reference to gender stereotypes.

56 Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, n 59 at 77; interACT, “Submission on United Nations Call for Information on Violence Against Women”.
57 Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, n 59 at 77.
59 InterACT, “Recommendations from InterACT: Advocates for Intersex Youth Regarding the List of Issues for the United States for the 59th Session of the Committee Against Torture” (INT/CAT/ICS/USA/2452, June 2016).
A history of preventative sterilizations and limited research on persons not subjected to sterilizations means that there is weak evidence associated with many intersex diagnoses, with insufficient data on cancer risks. For example, risk levels associated with some intersex diagnoses may be lower or comparable to women’s risk of breast cancer.

Insufficient regard may be given to the implications of treatment for the potential fertility of intersex people, especially where that potential is associated with a gender that does not match sex of rearing. For example, an assumption that a woman should not have testes may lead to surgery being performed, without her consent, and disregarding her future potential for fertility using novel technologies.

Forced sterilization of intersex children and adults is recognized as a violation of fundamental human rights, including the right to health, the right to information, the right to privacy, the right to decide on the number and spacing of children, the right to found a family and the right to be free from discrimination. United Nations human rights bodies have also found that forced sterilization is a violation of the right to freedom from torture and ill-treatment.

In other situations, deferrable medical interventions during infancy and early childhood may be intended to enable adult fertility, but necessity, timing, nature and evaluation of outcomes of such interventions lack clinical consensus. Potential for fertility aligned with sex of rearing may outweigh considerations of individuals’ right to bodily integrity, and presume their future interests. Both situations seek to construct bodies that more closely fit narrowly-defined definitions of “normal” female or male bodies.

Medical interventions are often purported to be necessary in order to comply with gender stereotypes, and social and cultural norms for male and female bodies. For example, an Australian court case in 2016 made reference to gender stereotypes including mention of a young intersex child’s Barbie bedspread and Minnie Mouse underwear in justifying the child’s sterilization.

Some have tried to justify surgeries by highlighting the potential discrimination that individuals may face due to their intersex variations. Alleged “psychosocial” rationales also include parental distress, fear of discrimination and stigmatization, potential so-called “confusion” around future gender identity, stigma associated with having genitalia that does not match sex of rearing, and marriage.
prospects. In some countries, legislation prohibiting female genital mutilation may contain explicit exemptions permitting so called “normalizing” surgeries on intersex children, despite provisions stating that social, cultural and religious customs or practices cannot justify their necessity. Fear of discrimination can never justify human rights abuses. Attempts to resolve such fears through surgery have been described as a “circular argument”. States have a responsibility to actively combat discrimination and stigma, including through education and awareness raising campaigns, as one of the root causes of these harmful practices.

Medical procedures may sometimes be justified on the basis of alleged health risks or benefits, but these may be proposed on the basis of weak evidence and without exploring alternative measures that protect physical integrity and respect autonomy. Loose conceptions of medical necessity or therapeutic treatment may facilitate social and cultural rationales, and other rationales that lack evidence of urgent need.

There is no clinical consensus on timing, however, surgeries are sometimes justified based on timing. Rationales alleging that early surgeries have better outcomes lack evidence. The idea that early surgery will remove a risk of trauma, and that children will be unable to recall surgery may not take into account the consequences of early surgery, including trauma, a need for follow-up and potential further surgery. Early surgery also presumes children’s future interests. As stated by the Committee on Bioethics of the Council of Europe, there is no guarantee that early surgery “will be certain to coincide with the child’s actual identity, sexual interests, and desires for bodily appearance”. There is evidence to suggest that, in some cases, surgical interventions may deliberately proceed early to preempt the legal capacity of a child. Beliefs about a child’s best interests, including under the guise of medical necessity, must not outweigh their right to free and informed consent.

Treatment may have a financial rationale, such that access to treatment may be subject to an age-dependent financial deadline that puts pressure on parents to agree to surgery earlier than it might otherwise occur. This includes a Canadian report where unwanted surgery took place in adolescence, prior to attaining an age of majority, as any further deferral would have ended access to subsidized treatment. Financial rationales also include perceptions that surgery may be more cost-effective than ongoing psychosocial support and resourcing for peer support.

Medical interventions may also in some cases have religious justifications. In 2019, the Congregation for Catholic Education called for acceptance of medical authority to determine sex assignment and “therapeutic” medical interventions on children with variations of sex characteristics to establish “the person’s constitutive identity”, stating that neither parents nor society should decide. In pre-empting individuals’ natural

75 Asia Pacific Forum of National Human Rights Institutions, n 21, p 74.
76 Office of the High Commissioner for Human Rights, n 1 at 1.
77 Community Affairs References Committee, Senate of Australia, n 15, p 74.
78 Zillén et al, n 46 at 42–43.
81 Zillén et al, n 46 at 42.
82 Carpenter, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8, p 476.
83 Special Rapporteur on the rights of persons with disabilities, n 62 at 14, 41.
85 Australian Human Rights Commission, n 84, p 20.
86 Congregation for Catholic Education, n 32 at 13.
physical development, this appears to diverge from historical teachings on “hermaphrodites”.87 Islamic teachings appear to endorse “corrective” interventions and individual choice.88 Other religious bodies have sought to distance intersex people from LGBT people without comment on medical intervention.89 Even in low income countries where access to medical treatment is challenging, parents and families face pressure to consent to medical interventions.90 The Kenya National Commission on Human Rights has called on religious institutions to promote acceptance of intersex persons.91


93 World Health Organization et al, Eliminating Female Genital Mutilation, n 96, p 5.

94 World Health Organization et al, Eliminating Female Genital Mutilation, n 96, p 6.


96 Committee on the Elimination of Discrimination against Women and Committee on the Rights of the Child, n 99 at 12.


98 Asia Pacific Forum of National Human Rights Institutions, n 21, pp 74–75.

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**FEMALE GENITAL MUTILATION AND INTERSEX GENITAL MUTILATION**

Female genital mutilation (FGM) refers to all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons.92 The practice persists due to normative ideas about women’s bodies, normative and unequal gender roles, and social control over women,93 including the harmful notions that women must undergo the ritual in order to be eligible for marriage or as a rite of passage to adulthood.94 In some cases, parents may be motivated to consent to female genital mutilation because they see other parents doing so; women subjected to the procedure may also exert pressures that promote conformity and ostracize others.95 The World Health Organization and other UN bodies recognize that medicalization of FGM, for example as a form of harm reduction, does not justify a procedure or make it less severe.96 FGM performed by health care professionals without the free and informed consent of girls is a human rights violation, whether conducted or not by health care professionals.

Legal experts, policy-makers and advocates have drawn parallels between female genital mutilation and practices to modify the genitals of children with intersex variations.97 In some cases, exemptions to legislation prohibiting female genital mutilation may contain exemptions permitting those practices on intersex infants and children.98

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FEMALE GENITAL MUTILATION AND INTERSEX GENITAL MUTILATION

Non-medical rationales are evident in decision-making about procedures that irreversibly modify the external genitalia of intersex children, including normative ideas about female and male bodies, claims regarding social, community and parental acceptance, social pressure, marriage prospects, and gender stereotyping. Some experts describe such practices as “intersex genital mutilation”. This language reflects the parallels between the two practices, including parallels in justifications for procedures not based on urgent medical necessity. In concluding observations on South Africa, the Committee on the Rights of Child has called for the prohibition of harmful practices including intersex genital mutilation.

Intersex-led organizations support access to affirmative treatments if and when individuals are able to provide informed consent. This can be contrasted with female genital mutilation, where personal informed consent is not considered to be a valid rationale. Approaches towards female genital mutilation can also be contrasted with gender-affirming treatments for transgender people where irreversible interventions require personal informed consent as a minimum requirement.

Societal beliefs and gender stereotypes are often reflected in the beliefs of doctors, as well as parents of intersex children, who may encourage and/or give their agreement to surgical and other procedures, even where such procedures may be medically unnecessary, irreversible, and violate human rights standards. According to the Committee on Bioethics of the Council of Europe, parental consent or any desire for such interventions is inherently problematic due to the impact on children’s rights to autonomy and physical integrity. Parents of children with intersex traits often face pressure to agree to such surgeries or treatments on their children, and sometimes receive partial information or misinformation, without having information on alternatives or the potential negative and long-term consequences of these procedures. Parents may lack contact with peers and intersex adults, and lack affirmative portrayals of intersex bodily diversity. Research shows that decision-making by potential parents on surgery is markedly different depending on the counselling approach and language adopted by healthcare practitioners, and that, faced with uncertainty or the absence of pathways supporting non-surgical approaches, doctors may steer discussions with parents towards surgery. In many countries, surgical interventions on children may be funded by insurance or the State, while psychological support for individuals and families, and access to reparative treatments, may be limited or unfunded.
Claims have been made about changes to clinical practices, including fewer surgical interventions, and improved surgical techniques. In some cases, claims of technical obsolescence and technical improvements to surgical methods are made in support of claims that clinical practices have changed. Claims of improved surgical techniques can never justify unnecessary or deferrable medical interventions on an individual without their consent.

There is little transparency about actual surgical practices, but available statistical data in recent years show no decrease in numbers of surgeries. Some intersex human rights defenders state that clinical practices are underpinned by a lack of transparency. In the United States, inconsistencies have been reported between perception and reality where surgeries and other medical treatments remain more prevalent in practice than some clinicians believe to be the case. Evidence, for example from Australia, shows that human rights violations continue to take place despite clinical guidelines and statements that recommend against early interventions, despite claims of “trends” away from early surgeries, and despite advice against a procedure “unless a condition poses a serious risk” to health. The German Medical Association has identified that clinical guidelines are non-binding, no oversight exists, and adherence is uncertain; forced and coercive medical interventions persist.

Intersex human rights defenders have challenged unnecessary medical interventions for more than twenty years. Community statements include the Malta Declaration of the third International Intersex Forum in 2013, and regional statements. These make a range of calls, including for the prohibition of unnecessary or deferrable medical interventions, provision of effective oversight, and the development of standards of care. Civil society organizations have reported on the local situation in most regions of the world including, for example, by SIPD Uganda, Beyond the Boundary – Knowing

117 Althoff, n 13, p 408; Loeffer, n 114.
In 1999, the Constitutional Court of Colombia determined that an eight-year old child should not undergo feminizing surgeries, on the basis that surgery was not urgent and that the child’s right to autonomy, increasing with age, should be respected after age five.\textsuperscript{137} This judgment was confirmed in another case in 2008.\textsuperscript{138} While considered progressive at the time, it has been criticized for expediting early surgeries.\textsuperscript{139} The Chilean Ministry of Health introduced a prohibition in 2015 on early non-urgent surgeries without the consent of the person concerned.\textsuperscript{140} However, this was rescinded some months later by a policy supporting substitute consent by parents, including for non-urgent genital surgeries.\textsuperscript{141} The Madurai Bench of the Madras High Court has also called in 2019 for a prohibition of “sex reassignment” surgeries on intersex infants in India, stating that the “consent of the parent cannot be considered as the consent of the child”.\textsuperscript{142} 2018 Portuguese legislation protects children until their gender identity is established; however, intersex organizations have expressed concern about a lack of attention to both the child’s capacity and agency in determining gender identity, and to the legality of early necessary medical interventions.\textsuperscript{143}

Only Malta has introduced protection from forced and coercive deferrable medical interventions, through recognition of the right to bodily autonomy. The law specifically prohibits “medical interventions driven by social factors without the consent of the minor”, with a later amendment enacting penalties commensurate with penalties for female genital mutilation.\textsuperscript{144} The Act has also required the provision of oversight, and the development of medical standards that comply with human rights norms. While Maltese reforms are considered good practice, there are few reports on implementation of the law, and alleged cases of unnecessary medical intervention persist.\textsuperscript{145}

Multiple regional and national reports have recommended an end to forced medical interventions and, in some cases, changes to medical classifications.\textsuperscript{146} In 2015, the Commissioner for Human Rights of the Council of Europe recognized a right for intersex persons to not undergo sex assignment


\textsuperscript{142} WP(MD) No4125 of 2019 and WMP(MD) No3220 of 2019 (Unreported, Madurai Bench of Madras High Court, Madurai Bench of Madras High Court, 22 April 2019) at 16–17.


\textsuperscript{144} Gender Identity, Gender Expression and Sex Characteristics Act 2018 at 14.


interventions. In 2016, the Asia Pacific Forum of National Human Rights Institutions stated that “fear and discrimination can never justify human rights abuses, including forced medical treatment”. The Committee on Bioethics of the Council of Europe (2017) issued a detailed critique of clinical protocols as part of a broader analysis on the rights of children in biomedicine, finding that current so-called “normalizing” practices lack evidence and necessity. The European Parliament adopted a wide-ranging resolution on the rights of intersex people in 2019, including a condemnation of “sex-normalising treatments and surgery” and a call for EU-funded research projects to ensure that that the human rights of intersex people are respected.

National human rights institutions have also published reports on the situation of intersex people, including in Argentina, Kenya and New Zealand. The Australian Human Rights Commission is currently conducting a study on protecting the rights of people born with variations of sex characteristics in the context of medical interventions. A statement by the Conference of German Ministers for Women and Equalities in 2014 equated surgeries to modifying the appearance of intersex genitalia with Female Genital Mutilation. It criticized medical intervention on intersex children based on a perceived need to assimilate or conform, under the guise of the “best interests” of the child, noting that the concept can be manipulated. The Conference also adopted a resolution on the rights of intersex people that indicates that parental consent is not possible for surgeries on girls that involve removal or cutting of the clitoris due to criminal code provisions on female genital mutilation.

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147 Council of Europe Commissioner for Human Rights, n 13.

148 Asia Pacific Forum of National Human Rights Institutions, n 21, p 86.

149 Zillén et al, n 46 at 78.

150 European Parliament, n 37 at 4.


152 Kenya National Commission on Human Rights, n 27.


154 Australian Human Rights Commission, n 84.

Violence and infanticide
• The right to security of the person, including freedom from injury to the body and the mind, or bodily and mental integrity is protected by the first substantive right in the Universal Declaration of Human Rights, article 3, as well as the International Covenant on Civil and Political Rights, article 9; and the Convention on the Rights of Persons with Disabilities, articles 16 and 17.\(^\text{156}\)

• All persons have the right to freedom from violence, and freedom from torture and ill-treatment.\(^\text{157}\)

• States have an obligation to investigate, prosecute alleged perpetrators, provide victims with remedy, address patterns of violence, and tackle root causes.

Evidence suggests that intersex infants and children may be subjects of infanticide and mutilation in multiple regions of the world, with documented cases of infanticide in East and Southern Africa and South Asia, and of mutilation in East Africa.\(^\text{158}\) As noted by intersex organization SIPD Uganda, the Kenyan national human rights institution and the Foundation for Human Rights in South Africa, intersex infants and their mothers may be considered witches, or victims of witchcraft; and children may be considered a curse or bad omen.\(^\text{159}\)

Reports from South Africa and Kenya state that infanticide may traditionally occur at birth if an intersex variation is evident in the baby, performed by midwives in the belief that an infant with ambiguous genitalia is cursed or bewitched.\(^\text{160}\) In East Africa, the appearance of an obviously intersex infant may be difficult to conceal due to traditional practices that celebrate a birth.\(^\text{161}\) Research in Kenya by Disability Rights International suggests that beliefs in curses are also experienced by parents of children with disabilities, suggesting that these beliefs are associated with visible physical difference.\(^\text{162}\) A report published on African children accused of witchcraft by UNICEF has identified that “abnormal births” are associated with infanticide and abandonment.\(^\text{163}\)

Non-governmental organizations, academic and governmental institutions have collaborated in work in South Africa and in a side-event of a session of the African Commission on Human and Peoples’ Rights to identify and tackle these violence and infanticide of intersex children.\(^\text{164}\)

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\(^\text{156}\) Committee on Civil and Political Rights, n 43 at 2–3, 9; Yogyakarta Principles, n 25, p 10.


\(^\text{159}\) Support Initiative for Persons with Congenital Disorders, n 125, supra, pages 6 to 7; Foundation for Human Rights et al, n 114 supra.


\(^\text{164}\) Botha and Sehoole, n 165; Centre for Human Rights and University of Pretoria, n 33; Foundation for Human Rights et al, n 163.
In China, cases of abandonment and attempted infanticide have also been reported. The intersex group “Beyond the Boundary” has expressed concern that this is associated with social norms favouring the birth of boys.

Cases of murder, mutilation, harassment and stigmatization of adolescents and adults have been reported. In 2015, news of the murder and mutilation of an adolescent was reported in Kenya. In 2017, disturbing video footage emerged of the assault and potential rape in Nigeria of an adolescent intersex boy, tagged as a witch. In the case of Richard Muasya v. the Hon. Attorney General and others before the High Court of Kenya in 2010, Richard Muasya was found to have suffered inhuman and degrading treatment through humiliating and invasive body searches while in prison.

Intersex organizations and the UNHCR report that intersex persons may flee persecution and violence due to their physical characteristics, and seek asylum. Intersex organizations have also identified cases where individuals who speak up about intersex human rights issues have been forced to flee. Little evidence for this appears in literature on LGBTI refugees, which frequently assumes that individuals fit specific identity categories. As with policies designed to protect individuals in places of detention, policies aimed at protecting people with particular identities may fail to protect individuals with particular physical characteristics. Due to their physical characteristics, intersex asylum seekers may not face barriers associated with “proof” of identity. However, they may fear disclosure, exposure and violence from diaspora communities.

Australian sociological research published in 2016 found that survey respondents whose intersex characteristics were visible to strangers were more likely to experience discrimination; these experiences including reporting of violence, insults and discrimination that associated such characteristics with being LGBT or having a disability. Research on intersex persons in Kenya for a national taskforce inquiry found that a majority of respondents had a physical appearance that did not fit expectations associated with the sex recorded on their birth certificates.


166 Beyond the Boundary - Knowing and Concerns Intersex, n 126 at 6,17.


170 Office of the Attorney General and Department of Justice, n 29 at 14.
Stigma and discrimination in healthcare
• Everyone is entitled to enjoy the right to health. Children have the right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.

• The right to sexual and reproductive health is an integral part of the right to health, closely linked to enjoyment of rights to freedom from violence and coercion, to bodily integrity, to non-discrimination, and access to education, information and appropriate health services.

• Discrimination in healthcare settings is widespread, and violates the most fundamental human rights. Users of healthcare services should be empowered to demand their rights and hold service providers accountable for discrimination-free healthcare. Access to effective mechanisms for redress and accountability must be guaranteed. Healthcare professionals must be provided with guidance and practical tools to raise awareness of human rights standards for non-discrimination in healthcare.

Because their bodies do not fit sex and gender norms, intersex people face stigma and discrimination in access to healthcare. The right to health of intersex persons is impacted by stigma and bias within healthcare systems, poor quality healthcare, institutional violence, lack of access to medical records, lack of training of medical professionals, lack of research on the long-term health outcomes and needs of intersex people, and a lack of standards of care that are respectful of the rights of intersex people.

Intersex organizations and human rights institutions have called for medical providers to defer decision-making on non-emergency invasive and irreversible interventions until children are old enough to determine themselves whether or not they wish to undergo a procedure. In some important cases, early medical interventions may sometimes be necessary for the physical health of a child, and justified through clear evidence of medical necessity and urgency. The Committee on Bioethics of the Council of Europe states that these situations are:

On the scientific question of whether intervention is necessary, only three medical procedures have been identified as meeting that criteria in some infants: (1) administration of endocrine treatment to prevent fatal salt-loss in some infants, (2) early removal of streak gonads in children with gonadal dysgenesis, and (3) surgery in rare cases to allow exstrophic conditions in which organs protrude from the abdominal wall or impair excretion.

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177 World Health Organization, n 10, pp 1, 18 and 27.
179 Justicia Intersex and Zwischengeschlecht.org, n 12 at 22.
180 Support Initiative for Persons with Congenital Disorders, n 125.
181 Jones et al, n 179, p 113.
184 Zillén et al, n 46 at 42; Garland and Diamond, n 73.
185 Human Rights Watch, n 65, pp 154–158.
186 Zillén et al, n 46 at 43.
Some individuals may require medical care when able to choose, for physical health or psychological well-being. In some cases, specific intersex variations may be associated with additional specific health needs, for example, congenital adrenal hyperplasia is associated with adrenal insufficiency, and sex chromosome variations may be associated with physical and cognitive issues. The consequences of prior medical intervention may require ongoing medical treatments that are also associated with specific risks. For example, persons subjected to gonadectomies invariably require lifelong hormone replacement to maintain health. Individuals subjected to forced and coercive interventions in childhood may lack support to remedy or manage the impact of those interventions in adulthood. Risks and costs associated with ongoing treatments may be underestimated or poorly disclosed when initial treatment is determined. Individuals may be obligated to pay for ongoing hormone replacement and associated health care, and any reparative treatments.

These health needs may be overshadowed by a focus on individuals’ identities or physical sex characteristics, and a focus on “fixing” intersex traits in place of living with intersex bodies. In all cases, intersex-led and medical organizations stress the importance of peer support, psychological support and counselling for individuals, families, and prospective parents.

Intersex adults have reported discrimination in access to care based on their intersex traits, including lack of access to necessary screening and procedures, prejudice, and an absence of health professionals trained on the specific health needs they may have. Medical practices focused on surgical interventions on infants and young children may be accompanied by a lack of resources or attention to the psychological needs of individuals and their families, and adolescent health needs. Health services designed to meet the needs of adults who identify as LGBT, or transgender children do not, by virtue of that fact, have capacity or skills to manage the healthcare of infants, children, adolescents or adults with intersex variations and their families.

In some contexts, access to healthcare may be financially prohibitive irrespective of age. In others, financial rationales may mean that treatment is agreed by parents earlier than it should, without an individual’s personal, informed consent.


188 Human Rights Watch, n 65, pp 6, 25 and 52.


194 Liao L-M and Simmonds M, “A Values-Driven and Evidence-Based Health Care Psychology for Diverse Sex Development” (2013) 5 Psychology & Sexuality 83 at 1; Liao et al, n 110 at 1; Human Rights Watch, n 65, p 154.


196 Regmi, n 127.
Some intersex people have reported that prior experience of human rights violations in medical settings has hindered their later engagement with health services.\(^{197}\) A 2016 clinical statement identifies that the “practice of withholding medical history details, along with the possibility of negative medical experiences likely contributes” to a disengagement with clinical services.\(^{198}\) Many individuals also lack the information they need about their diagnosis and peer support to satisfactorily manage their health and well-being.\(^{199}\) In some cases, there are reports of lack of access by intersex persons to certain procedures, treatments or screening deemed applicable only to one sex, because they are registered as another sex.\(^{200}\) A 2017 study found that pathologizing language itself acted as a barrier to healthcare access.\(^{201}\) Intersex organizations also highlight adverse consequences of medical classifications and diagnostic categories on perceptions of intersex bodies, where the labelling of intersex traits as disordered or abnormal contributes to discrimination and stigma, as well as the encouragement of surgeries and other interventions.\(^{202}\)

UN and regional human rights bodies, intersex human rights defenders and researchers, and Physicians for Human Rights have expressed concern at the unnecessary pathologization of intersex variations. Human rights institutions, researchers and human rights defenders have identified a relationship between pathologization and disease classifications, on the one hand, and human rights violations against intersex people, on the other.\(^{203}\) The World Health Organization has recognized the existence of human rights violations against intersex people within the contexts of forced sterilization\(^{204}\) and sexual health.\(^{205}\) The International Classification of Diseases 11 (ICD-11) introduces new language that regards intersex people as having “disorders of sex development” while retaining pejorative language such as “pseudo-hermaphrodite” in addition to clinical descriptions that promote or facilitate early irreversible surgeries.\(^{206}\) Intersex organizations and researchers are advocating for changes to be made to these classifications.\(^{207}\)


\(^{198}\) Lee et al, n 58 at 170.


\(^{200}\) Dreger A, Bye, Max. (We Already Miss You.) (4 February 2008), http://alicedreger.com/Max viewed 8 December 2018.

\(^{201}\) Johnson et al, n 202.


\(^{204}\) World Health Organization et al, Eliminating Forced, Coercive and Otherwise Involuntary Sterilization, An Interagency Statement, n 67.

\(^{205}\) World Health Organization, n 10.


WHO ARE INTERSEX PEOPLE?

The pathologization of intersex variations as disorders has led to the use of prenatal interventions, and genetic testing and deselection for multiple intersex traits. Prenatal hormone treatments may be used – wrongly – to reduce the physical and psychological manifestations of an intersex variation, including to try to modify physical characteristics, reduce “behavioural masculinization” and change sexual orientation. Such interventions are experimental and lack evidence of long-term outcomes, while there is also evidence of poor developmental outcomes. Prenatal and in vitro tests to ensure that sex characteristics conform to stereotypical gender norms reinforce stereotypes and perpetuate discrimination against intersex people on the basis of their sex characteristics, and sex and gender norms.

The Convention on the Elimination of Discrimination Against Women calls for the elimination of practices based on stereotyped roles for men and women. A 2011 UN interagency statement urged States to combat gender-biased sex selection, describing the consequences of gender-biased sex selection as “an unacceptable manifestation of gender discrimination against girls and women and a violation of their human rights. The statement called for legal and policy measures and advocacy and awareness activities to combat sex selection, including communication and community mobilization that address root causes. The statement also called for data collection on the phenomenon, in addition to research on causes and impact, and promotion of the responsible use of technologies.

The Council of Europe Commissioner for Human Rights has stated that prenatal hormone treatments and genetic testing intended to eliminate intersex embryos are “discriminatory sex selection” and incompatible with “human rights standards due to the discrimination perpetrated against intersex people on the basis of their sex characteristics”.

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213 Office of the High Commissioner for Human Rights, UNFPA, UNICEF, UN Women and World Health Organization, Preventing Gender-Biased Sex Selection: An Interagency Statement (World Health Organization (WHO), Geneva, 2011). The Statement also calls to “Ensure women’s access to safe abortion and other services – efforts to manage or limit sex selection should also not hamper or limit access to safe abortion services. This should be part of broader efforts to protect the right of women to have access to legitimate sexual and reproductive health technologies and services.”

214 Council of Europe Commissioner for Human Rights, n 13 at 30.
Legal recognition, including registration at birth
The Convention on the Rights of the Child (article 7), the International Covenant on Civil and Political Rights (article 24) and Convention on the Rights of Persons with Disabilities (article 18(2)) require that children be registered immediately after birth, with a name and the right to acquire a nationality, but do not require States to register sex or gender.\textsuperscript{215}

The Yogyakarta Principles plus 10 recommend an end to the registration of the sex or gender of the person in identity documents and as part of their legal personality, while proposing interim arrangements that include a multiplicity of gender markers.\textsuperscript{216}

Intersex people face barriers in having their births registered, in changing sex or gender markers on official documents, and some also report being forced into unwanted sex or gender categories. In some countries, parents and individuals have had difficulty in registering the birth of intersex persons, and in some cases registration has been made dependent on parental consent for a child to undergo unnecessary and irreversible surgeries, with such two cases reported in Argentina.\textsuperscript{217} In the case of Richard Muasya v. the Hon. Attorney General and others before the High Court of Kenya, an intersex individual, Richard Muasya, had no identity documentation and did not complete schooling, but was found to be responsible for obtaining his own birth certificate, after a failure of his parents to obtain one at the time of his birth.\textsuperscript{218} The same court later adjudicated in the case of a five-year old child and required authorities to issue a birth certificate.\textsuperscript{219}

In some jurisdictions, such as France, birth registration processes may facilitate the late registration of an intersex child, for example, where sex of rearing may only be established after genetic and other testing.\textsuperscript{220} Intersex organizations have identified risks and benefits associated with such regulations. While allowing more time to determine the most appropriate sex of rearing for an intersex child, or even involve a child in a decision about sex assignment, the imminent approach of a deadline may encourage surgical or hormonal procedures in an attempt to reinforce sex of rearing.\textsuperscript{221} In Malta, determination of a female, male or non-binary gender marker can be delayed until age 18.\textsuperscript{222}

No early medical intervention is certain to coincide with a child’s future identity or desires.\textsuperscript{223} Like others, intersex people may face barriers and discrimination if they wish to or need to amend sex markers on birth certificates and official documents. Processes in some countries allow for changes to initial birth registration if an initial sex of rearing is discovered to be incorrect or inappropriate. A 2018 Kenyan intersex taskforce report found that a majority of intersex persons surveyed had birth certificates, but recorded sex frequently conflicted with physical appearance, limiting access to ID cards.\textsuperscript{224}


\textsuperscript{216} Yogyakarta Principles, n 25, p 9.

\textsuperscript{217} Justicia Intersex and Zwischengeschlecht.org, n 12 at 22.


\textsuperscript{221} OII Francophonie, n 225.


\textsuperscript{223} Zillén et al, n 46 at 42; Garland and Diamond, n 73, p 92.

\textsuperscript{224} Office of the Attorney General and Department of Justice, n 29 at 14.
In some cases, courts have determined the ability of intersex persons to change sex classification. In 2008, the Supreme Court of the Philippines determined that an intersex man had the right to change the sex marked on his birth certificate from female to male. The decision was based on naturally occurring physical changes as his body matured; he “had allowed ‘nature to take its course’ and had not interfered with what ‘he was born with’”. In this example, natural changes to sex characteristics from puberty aligned with his desired legal sex registration. In a different case, an Indonesian intersex man was acquitted on appeal to the country’s Supreme Court after an accusation of fraud in relation to his gender brought by his wife.

In some jurisdictions, surgical or age requirements may be imposed, in violation of human rights norms. In Uganda, for example, the Registration of Persons Act 2015 permits intersex children to be registered and have their sex registration changed through the recommendation of a medical practitioner following a surgical procedure. The Act further refers to such children as “hermaphrodites”, a term that many intersex persons find stigmatizing and dehumanizing, and the provisions of the Act do not apply to persons who became adults prior to its commencement.

Imposing surgical requirements as a precondition of legal recognition amounts to coercive treatment, and so violates rights to bodily integrity, self-determination and freedom from torture and cruel, inhuman and degrading treatment. Surgical requirements are particularly harmful where an inappropriate initial sex assignment was itself imposed through unwanted and irreversible changes to sex characteristics.

Some intersex (and non-intersex) people feel that they were forced into binary sex and gender categories that do not fit them, and some individuals express a desire for legal recognition as intersex. Some countries permit at least some official documents to record a third or other sex or gender classifications. In some cases, such as in the U.S. State of New York, this appears driven by demands that birth registration reflect a particular understanding of biology. The German Government has enacted a new classification called “diverse”, available only to some intersex people with medical certification. This approach has been criticized by intersex and transgender organizations, including for failing to address forced medical interventions, medicalizing access to legal documentation, and a failure to make the new classification available to non-intersex persons. Australia has offered an X marker on passports for intersex people since 2003, and formally maintained a more broadly available “Indeterminate/ Intersex/Unspecified” classification since 2011. Since 2015, intersex and transgender organizations in Australia have jointly called for that classification to be renamed “non-binary”. A federal case of an intersex person who identifies as non-binary is pending in the US.
Many intersex people feel forced into association with new, third or non-binary sex and gender categories.\(^{235}\) Latin American and Caribbean, and Australia/New Zealand intersex community declarations reject the idea that intersex is a third sex.\(^{236}\) The Darlington Statement (Australia/New Zealand) states that “attempts to classify intersex people as a third sex/gender do not respect our diversity or right to self-determination” and have been harmful.\(^{237}\)

Human rights defenders fear that, despite assertions that new categories offer parental choice and reduce risk of surgeries, stigma and fear of disclosure may drive surgical interventions to make children with intersex characteristics appear more typically male or female.\(^{238}\) Some intersex and other human rights defenders call for the removal of all sex and gender markers from identification documents.\(^{239}\) For so long as they remain, intersex organizations recommend that intersex people should never be automatically categorized into third or non-binary categories of sex or gender, and that such categories should be universally available.\(^{240}\) They also recommend that, while legal sex or gender classifications continue to be assigned on a compulsory basis at birth, children receive a “best fit” assignment to either male or female, without medical intervention, acknowledging that the classification can later change if necessary or requested by the person concerned.\(^{241}\) Intersex community declarations typically support access to non-binary and alternative sex or gender classifications for all individuals, whether they are intersex or not.\(^{242}\)

In a statement on embracing diversity and protecting trans and gender diverse children and adolescents, UN Treaty Bodies, Independent Experts, and representatives of regional human rights institutions have called on States to “facilitate quick, transparent and accessible legal gender recognition and without abusive conditions, guaranteeing human rights for all persons, respectful of free/informed choice and bodily autonomy” without coercive requirements such as sterilization or mental health diagnoses.\(^{243}\)

Argentina, Malta and an increasing number of other jurisdictions have introduced legislation and regulations enabling gender recognition through simple administrative processes. The Argentinian law, enacted in 2012, is low cost and requires no medical certification.\(^{244}\) Maltese regulations, introduced in 2017 also allow for self-determination.\(^{245}\)

\(^{235}\) Androgen Insensitivity Syndrome Support Group Australia et al, n 124; Participants at the Latin American and Caribbean Regional Conference of Intersex Persons, n 124; Garland and Travis, n 13 at 13–15; Althoff, n 13, p 395.

\(^{236}\) Participants at the Latin American and Caribbean Regional Conference of Intersex Persons, n 124.

\(^{237}\) Androgen Insensitivity Syndrome Support Group Australia et al, n 124 at 8.

\(^{238}\) Council of Europe Commissioner for Human Rights, n 13 at 38; Carpenter, “The ‘Normalisation’ of Intersex Bodies and ‘Othering’ of Intersex Identities”, n 8, pp 485–486; Garland and Travis, n 13 at 14.

\(^{239}\) Third international intersex forum, n 123; Androgen Insensitivity Syndrome Support Group Australia et al, n 124 at 8; Participants at the Latin American and Caribbean Regional Conference of Intersex Persons, n 124.

\(^{240}\) Third international intersex forum, n 123; Androgen Insensitivity Syndrome Support Group Australia et al, n 124.

\(^{241}\) Third international intersex forum, n 123; Androgen Insensitivity Syndrome Support Group Australia et al, n 124; Dreger, “Twenty Years of Working toward Intersex Rights”, n 6, p 61.

\(^{242}\) Third international intersex forum, n 123; Androgen Insensitivity Syndrome Support Group Australia et al, n 124; Participants at the Latin American and Caribbean Regional Conference of Intersex Persons, n 124.


\(^{245}\) Garland and Travis, n 13 at 6–7.
Discrimination and stigmatization
• International human rights law contains guarantees of equal access to the law and equal protection before the law without discrimination of any kind, as well as to remedy for violations of rights.\textsuperscript{246}

• UN mechanisms have recognized that discrimination may be, and commonly is, compounded by discrimination on multiple grounds, including sex, gender, gender identity, race, age, religion, disability, health, sexual orientation and economic status.\textsuperscript{247}

• Where forced, coercive and unnecessary medical interventions arise from sex and gender stereotypes, stigma and social prejudice, or are justified using social and cultural rationales, they violate the right to non-discriminatory treatment.\textsuperscript{248}

• The Convention on the Rights of Persons with Disabilities calls for the provision of reasonable accommodations, where necessary in order to promote equality and eliminate discrimination.\textsuperscript{249}

Intersex persons are often subjected to discrimination and abuse if it becomes known that they are intersex, or if they are perceived not to conform to sex and gender norms. Anti-discrimination laws do not typically ban discrimination against intersex persons, leaving them vulnerable to discriminatory practices in a range of settings, including access to education, public services and employment.\textsuperscript{250} The available data show that intersex people may have high rates of poverty, associated with high rates of early school leaving, stigmatization and discrimination.

An East African baseline survey published in 2016 based on interviews with 120 participants, including intersex people, parents, medical practitioners and community leaders, found that, in Uganda and other East African countries, 90 per cent of the intersex youth interviewed reported that they were forced to drop out of school due to stigma and discrimination from students and staff associated with their physical development during puberty.\textsuperscript{251} Students faced problems in accessing sanitation, including toilets, showers and changing rooms. A 2018 Kenyan intersex taskforce survey also found very high levels of early school leaving, “due to negative peer pressure and societal stereotyping”.\textsuperscript{252}

A 2015 Australian sociological study with a convenience sample of 272 participants born with atypical sex characteristics found that 18 per cent only completed primary school.\textsuperscript{253} Most early school leavers left between ages 12 to 16, during years associated with puberty, hormone treatments and, in some cases, genital surgeries and distress associated with medical treatment. School curricula were non-inclusive, and counselling services unaware. Experiences of bullying from students and staff, notably on the basis of atypical physical characteristics, developmental delays or medical leave were common and well-being risks were high. Few governments have addressed the needs of intersex youth in school


\textsuperscript{250} Office of the High Commissioner for Human Rights, n 33.

\textsuperscript{251} Support Initiative for Persons with Congenital Disorders, n 125 at 16.

\textsuperscript{252} Office of the Attorney General and Department of Justice, n 29 at 159–160.

and other educational contexts. An example by the South Australian government focuses solely on issues of identity and gender transition.254

The Australian study found high levels of poverty amongst survey participants, and lower than typical levels of participation in the workforce. Multiple reports have found evidence of discriminatory treatment in workplaces and in social services, while the negative impacts of surgeries and other interventions, in addition to poor information provision on associated health risks, can have a severe impact on the work and professional trajectories of intersex people.

Multiple women athletes with variations of sex characteristics have been disqualified or humiliated due to their characteristics.255 Many have had their lifelong legal and social status and identities as women questioned as a consequence of policies that single them out for exclusion.256 In the recent past, women athletes have been subjected to chromosomal testing, in some cases revealing that they do not possess two X chromosomes.257 Following criticism of the discriminatory nature of chromosome testing, these policies were later abandoned, but international and national sporting federations subsequently introduced policies restricting participation in women’s sport by women with “hyperandrogenism” (testosterone levels exceeding a certain threshold). International sporting bodies have mandated that national bodies “actively investigate any perceived deviation in sex characteristics”,258 thus targeting women who fail to meet gender stereotypes.259 Restrictions on participation by women with hyperandrogenism were suspended following the Court of Arbitration in Sport 2015 interim judgement in Chand v. Athletics Federation of India and the International Association of Athletics Federations,260 but then reintroduced in certain athletics events in 2018.261

South African athlete Caster Semenya challenged the IAAF’s 2018 “differences of sex development” regulations before the Court of Arbitration in Sport.262 During the course of that challenge, the IAAF modified the regulations to focus on only on testosterone but also, in a return to earlier methods of sex verification, based on chromosomes.263 CAS adjudicated a majority decision in favour of the IAAF.264 At the time of writing, Semenya had appealed the decision.265

Hyperandrogenism and differences of sex development policies have led to suggestions that women athletes who are perceived not to conform to certain gender stereotypes- i.e. in particular stereotypes based on binary/biological sex characteristics- should or could be subjected to forced or coercive

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254 Department for Education and Child Development and South Australia, “Transgender and Intersex Student Support Procedure”.
255 Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, n 44 at 55–57.
258 Jordan-Young et al, n 194 at 1.
261 International Association of Athletics Federations, “Eligibility Regulations for Female Classification (Athletes with Differences of Sex Development)” (IAAF, 23 April 2018).
treatment in order to continue to compete. Cases have already been recorded of coercive interventions for hyperandrogenism, including athletes required to undergo a gonadectomy (the removal of their reproductive organs) and partial clitorectomies (a form of female genital mutilation) in the absence of symptoms or health issues warranting those procedures.

There is insufficient scientific evidence to establish that women in such cases are afforded a “substantial performance advantage” warranting exclusion. Having an intersex trait does not in itself entail better performance, whereas other physical variations that do affect performance, such as body mass, height and muscle development, are not subjected to such scrutiny and restrictions. In the case of Caster Semenya, the Court of Arbitration for Sport determined in 2019 that its role was to determine whether the regulations set by the International Association of Athletics Federations (IAAF) were necessary, reasonable and proportionate and could not consider the adequacy of decision-making processes or consequential scientific integrity of the evidence put to it.

In 2005, South Africa included intersex within a broad definition of sex, in the Promotion of Equality and Prevention of Unfair Discrimination Act, 2000. In 2013, Australia included the attribute of “intersex status” within the Sex Discrimination Act; however, despite the legislation referring to individuals’ physical features, the attribute has frequently been imputed to refer to an identity group. Intersex organizations in that country have called for effective protections from discrimination on the ground of “sex characteristics”.

The Maltese Gender Identity, Gender Expression and Sex Characteristics Act that prohibits surgery and treatment on the sex characteristics of minors without their informed consent also prohibits discrimination on the ground of sex characteristics. Malta has also implemented an anti-discrimination policy in schools.

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268 Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, n 44 at 55–57; Jordan-Young et al, n 194.


272 Republic of South Africa, n 34.


274 Androgen Insensitivity Syndrome Support Group Australia et al, n 124 at B and 9.

275 Gender Identity, Gender Expression and Sex Characteristics Act 2018.

Access to justice and remedies
• The Convention against torture and other cruel, inhuman or degrading treatment or punishment requires that States ensure access to redress and compensation, including means for rehabilitation. 277 It has been recommended that States arrange for investigations of cases of surgical or other medical treatment reportedly carried out without individuals’ informed consent. 278

• The right to truth describes a set of principles for the protection and promotion of human rights through action to combat impunity. 279 General principles include the inalienable right to the truth, the duty to preserve memory, and the victim’s right to know, supported by guarantees to give effect to the right to know. 280

• The Yogyakarta Principles plus 10 recognizes a right to truth for victims of human rights violations on the basis of sex characteristics that should not be subject to statutes of limitations. 281

Intersex organizations have suggested that statutes of limitations unnecessarily limit access to redress for intersex individuals who have suffered unnecessary or inappropriate medical interventions without their consent during childhood or adolescence. 282 Precedents exist for the removal of such limits such as, in some jurisdictions, the removal of limitations in relation to child sexual abuse. 283 Access to justice also appears to have been limited by clinical assertions of consensus regarding medical practices, including the concept that procedures comprised the usual or best practices at the time. 284 To date, there are few successful instances of claims for redress. While clinical bodies have proposed, this century, that disclosure of intersex variations to individuals and their families must always take place, progress at changing historical practices of non-disclosure appears variable. 285 Non-disclosure can be expected to have a profound effect on individuals’ capacities to access justice for unnecessary interventions.

Successful legal cases where redress has been sought have occurred in Germany and Chile, and the Court of Arbitration of Sport. In the case of Re: Völling, in the Regional Court Cologne, Germany, Christiane Völling was awarded damages in 2008 for what the International Commission of Jurists have described as “an example of an individual who was subjected to sex reassignment surgery without full knowledge or consent”. 286 A second case was awarded in 2015 to Michaela Raab, by the Nuremberg State Court. The court dismissed a case against the surgeon, but found his colleagues and institution liable for damages. 287
In the case of Benjamín-Maricarmen, in Chile, a mother won a case before the country’s Supreme Court for “lack of service” in relation to her son, Benjamín. He had been raised female, and subjected to a sterilization procedure including the unnecessary removal of a male reproductive system during a procedure to manage a hernia, without consent of either the child or his parents. The applicant was awarded compensation for moral and psychological damages.

The 2015 interim judgement in Chand v. Athletics Federation of India and the International Association of Athletics Federations facilitated competition by women athletes in the related sporting events without the imposition of medical requirements.

In the case of M.C. v Aaronson, a young boy born with ovotestes was subjected to “feminizing” surgeries while a ward of South Carolina in the United States. The defendant in the case had previously written that feminizing intervention would be “catastrophic” in a child who later identified as a boy, however, clinical norms and the lack of regulation or prohibition of such surgeries led the claim to be later settled out of court. The growing documentation of contention and lack of consensus about such practices within medicine may impact future cases.

In many jurisdictions, intersex people lack access to justice and remedy for human rights violations. Cases also exist where courts have approved early interventions without safeguarding the rights of the child. In a 2016 decision, the Family Court of Australia found that parents could authorize the sterilization of their 5-year old child in the absence of evidence of medical necessity, and determined that this was better done before the child attained legal capacity. The judge described a prior clitorectomy and labioplasty as having “enhanced the appearance” of her genitalia; those prior procedures had not required court approval. A subsequent case in 2017 recorded that an adolescent had been prescribed testosterone to kickstart puberty without her informed consent or oversight; the judge made no comment on the inappropriateness of that prescription.

288 Centro de Derechos Humanos UDP and Godoy Peña, n 144.
289 CAS 2014/A/3759 Dutee Chand v Athletics Federation of India (AFI) & The International Association of Athletics Federations (IAAF) [2015] Court of Arbitration for Sport 2014/A/3759 (July 2015).
293 These procedures are generally considered to be forms of female genital mutilation. See the section on female genital mutilation.
Several countries have undertaken investigations of medical practices affecting intersex people, including Australia,296 France,297 Germany,298 and Switzerland.299 In a 2012 report, the German Ethics Council has recommended the establishment of a State compensation fund,300 but this has not been implemented.301 The French Human Rights Defender made a similar call, lacking implementation, in 2017.302 No actions appear to have yet been taken to prosecute alleged perpetrators of human rights violations.

The Committee on the Rights of the Child has expressed concern about a lack of redress and compensation in cases of medically unnecessary procedures on intersex children.303 Similarly, the Committee against Torture has expressed concern regarding a lack of adequate redress and compensation in cases of forced, involuntary or otherwise coercive or abusive treatments of intersex persons.304 The Committee on the Elimination of Discrimination against Women has called on States to adopt specific measures aimed at providing victims of forced sterilization with assistance to access their medical records, and investigate past practices, prosecute and adequately publish perpetrators and compensate victims.305

296 Community Affairs References Committee, Senate of Australia, n 15; Australian Human Rights Commission, n 84.
297 Senate, n 151.
298 German Ethics Council, n 151.
299 National Advisory Commission on Biomedical Ethics NEK-CNE and Switzerland, n 151.
300 German Ethics Council, n 151, p 155.
301 Committee on the Elimination of Discrimination against Women, “Concluding Observations on the Combined Seventh and Eighth Periodic Reports of Germany” (CEDAW/C/DEU/CO/7-8, 9 March 2017) at 24(e).
302 Moron-Puech, n 101, p 309.
Addressing root causes of human rights violations
• States have a duty to address the root causes of human rights violations. States have an obligation to challenge and modify social norms that underpin and justify harmful practices. 306

Lack of awareness, misconceptions, harmful social and religious attitudes, stigma and taboos perpetuate human rights violations, and prevent people from speaking out. Lack of visibility and misconceptions still impede access by intersex individuals and their families to information, peer support, legal services. Limited disclosure of historical and current medical practices also impacts on the credibility of victims of human rights violations. 307 Intersex advocates in Europe have also identified a lack of non-pathologizing information on intersex. 308 With a legacy of concealment of medical practices from individuals and from society, individuals have reported feelings of isolation, and a lack of words to describe their lived experiences and bodies. 309

Intersex human rights organizations play a vital role in providing support to intersex people and their families, educating and addressing stigmatization and discrimination, and collecting evidence of human rights violations. Intersex human rights defenders have also filmed documentaries and published memoirs to raise greater awareness. 310 Eric Lohman, an interACT board member and parent of an intersex child, published Raising Rosie in 2018, describing his family’s journey. 311 26 October has been designated by intersex organizations as Intersex Awareness Day, and 8 November as Intersex Day of Remembrance or Intersex Day of Solidarity. 312 The European InterVisibility project has translated intersex-related material into 27 languages, 313 and interACT published a media guide in early 2017, 314 which accompanied news coverage of the model Hanne Gaby Odiele.

In 2016, the United Nations Human Rights Office launched a new webpage, United Nations for Intersex Awareness, as part of its ongoing UN Free & Equal campaign for the rights of LGBT and intersex people. The site highlighted key human rights issues affecting intersex people, and hosted an awareness raising video that was watched by more than a million people on social media. The United Nations Development Program and the World Bank are developing “LGBTI Indicators” that, over time, may provide disaggregated data on the circumstances of intersex people. 315

306 Committee on the Elimination of Discrimination against Women and Committee on the Rights of the Child, n 99 at 57.
309 Dregger, “Twenty Years of Working toward Intersex Rights”, n 6, p 58.
INTERSEX HUMAN RIGHTS ORGANIZATIONS

It is only within the last 25 years that intersex-led organizations have established themselves and grown to provide peer support and challenge human rights violations. Intersex human rights defenders and intersex-led human rights organizations play a vital role in tackling stigma, misconceptions, social taboos and discrimination, and in documenting rights violations. According to a 2017 survey, their work includes systemic advocacy, community organizing, education activities, and social services, peer support and individual advocacy.316

The movement remains hampered by a lack of resources,317 subject to a reliance on volunteers, and systemic barriers to fundraising including a lack of funder awareness and misconceptions about the intersex population.318 A 2013 study identified that intersex-led organizations had distinctly different priorities to organizations that included intersex within a broader remit.319

Conclusions and way forward
CONCLUSIONS

Intersex people suffer violations of their rights to liberty, security, freedom from torture, harmful practices, experimentation, and discrimination. Few States have investigated human rights violations against intersex people. Stigma, societal taboos, lack of awareness have contributed to the invisibility of intersex people.

Intersex people face risks of unnecessary forced and coercive medical procedures from birth to adolescence and in adulthood, associated with limited or absent provision of information to the individuals concerned and their families, with terrible consequences. Medical practices are perpetuated through the unnecessary pathologization of intersex bodies, and limited disclosure of the impact of historic and current practices.

Intersex people face stigmatization and discrimination in education, employment, access to services. Intersex persons’ right to health is threatened by stigma and bias, lack of clinical training, and unnecessarily pathologizing clinical practices and classifications.

Some individuals have had difficulty obtaining legal identification documents because of a difficulty in establishing their legal status. Attempts to recognize intersex people in sex and gender classification systems have often failed to adequately recognize the diverse existing legal and social status of intersex people. In some cases, surgical requirements have been imposed on survivors of forced medical practices who seek a change to their legal status.

These violations continue to happen in a generalized climate of impunity. Few cases have succeeded where intersex people have sought redress. Reasons for this appear to include the impact of statutes of limitations, limited disclosure of medical information, and claims that medical norms that violate children’s rights provide satisfactory benchmarks.

States have an obligation to investigate human rights violations and provide redress and remedies. States are also under an obligation to address the root causes of human rights violations, including by tackling stigma, pathologization, and harmful social and cultural norms. There have been some positive developments to protect the human rights of intersex people, however a lot remains to be done. Below are some steps on the way forward.

WAY FORWARD

**Bodily Integrity, freedom from torture, right to health, autonomy and self-determination**

Multiple institutions including the Office of the United Nations High Commissioner for Human Rights, and UN and regional human rights mechanisms, have advised that States should, as a matter of urgency, protect the autonomy of intersex adults and children and their rights to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment.\(^{320}\)

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UN treaty bodies have made reference to these rights in calls to protect the right to bodily integrity, and autonomy and self-determination of intersex children, and ensure that no-one is subjected to harmful practices or unnecessary medical treatment during infancy or childhood. Treaty bodies have further called on States to ensure that all medical or surgical treatment during infancy or childhood are documented. This may involve the repeal of legislation, regulations and practices allowing any form of forced intervention or surgery. Treaty bodies further recommend the adoption of legislation to explicitly prohibit the performance of surgical or other medical treatment on intersex children unless such procedures constitute an absolute medical necessity, and until the children involved reach an age at which they can provide their free, prior and informed consent.

In collaboration intersex-led organizations and medical bodies, States should ensure the development and implementation of rights-based, lifetime health-care protocols for intersex children, and effective independent oversight. States should also ensure that individuals and their families have access to independent counselling and support.

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Regarding clinical classifications, multiple human rights institutions and experts have recommended that medical institutions review their policies and procedures on the pathologization of intersex characteristics. Medical classifications that pathologize innate variations of sex characteristics should be reviewed and modified, to ensure effective enjoyment of the highest attainable standard of health and other human rights, including freedom from harmful practices.

Medical institutions should formally end support for deferrable surgical and other procedures to modify the sex characteristics of children born with variations of sex characteristics. Research should meet the ethical and legal standard for use of human research subjects, and respect the human rights of intersex persons. Medical institutions should promote complete age-appropriate disclosure of information to children and youth, including details of independent peer support groups.

**Violence and discrimination**

A joint statement by UN and regional experts urges States to take steps to prohibit discrimination on the basis of sex characteristics, including in education, healthcare, employment, sports, places of detention, and access to public services, and address such discrimination through relevant anti-discrimination initiatives.

States should ensure that members of the judiciary, immigration officers, law enforcement, healthcare, education and other officials and personnel are trained to respect and provide equal treatment to intersex persons.

General Comment 23 by the United Nations Committee on Economic, Social and Cultural Rights states that, like all workers, intersex workers have the right to equal opportunity in workplaces, including in hiring, promotion and termination. Access to reasonable accommodations should be provided where necessary.

The UN special rapporteur on health has recommended that sporting authorities ensure that all individuals who wish to participate in sport are supported to do so, and should ensure that all individuals are able to play, without restriction, in line with their sex assigned at birth, and subject only to reasonable, proportionate and non-arbitrary requirements to play in line with the gender with which they identify.

Humanitarian protective mechanisms must acknowledge human rights violations including threats to life, torture, violence, stigmatization and discrimination faced by people born with variations of sex characteristics and their families, including intersex human rights defenders, and safeguard their right to refuge and asylum.

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327 Public statement of UN and regional human rights experts, n 2.
328 Inter-American Commission on Human Rights, n 36; Council of Europe Commissioner for Human Rights, n 13; Cabral and Carpenter, n 208; Physicians for Human Rights, n 208.
330 Public statement of UN and regional human rights experts, n 2.
331 Public statement of UN and regional human rights experts, n 2.
333 Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, n 44 at 55–57.
334 Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, n 44 at 58–61.
Legal recognition of sex and gender

International intersex community statements and the Yogyakarta Principles plus 10 call for an end to the unnecessary registration of sex or gender in personal identification documents; for so long as such registration is required, all people should be able to access male, female, non-binary and alternative classifications.335

For so long as sex or gender classifications are used on personal identification documents, intersex organizations have called for registration of intersex children as male or female, and for sex/gender classifications to be amendable through simple administrative procedures, upon request.336 Policy-makers should have regard to both the diversity of intersex people and the diversity of non-intersex people in making new sex/gender classifications available. Respect for self-determination requires respecting the right of intersex persons to be recognized as men and women, ensuring that new classifications are framed and named in a manner that does not adversely impact this population.337

Access to justice

UN treaty bodies and a joint statement by UN and regional experts have repeatedly called on States to investigate human rights violations against intersex people, gather data on their incidence, hold those found guilty of perpetrating such violations accountable, and provide intersex people subjected to abuse with redress and compensation.338 A UN interagency statement calls on States to recognize practices of coercive sterilization, and issue statements of regret or apology to victims as components of the right to remedy for these practices.339 The Yogyakarta Principles plus 10 calls on States to recognize the right of intersex people to truth, including the truth about their medical histories.340

Statutes of limitations should be amended to facilitate access to justice, and states should consider the establishment of compensation funds.341

Addressing root causes

States must address root causes of human rights violations against intersex people- These include harmful social and cultural norms and stereotypes, including beliefs about attributes required of men and women. UN treaty bodies have called on States to educate and train medical and psychological professionals on the range of sexual and related biological and physical diversity and/or the human rights of intersex people.342 The media should include the voices of intersex people and groups in newspaper, TV and radio coverage, and give an objective and balanced picture of intersex people and their human rights concerns.343

335 Third international intersex forum, n 123. Yogyakarta Principles, n 23, p 9
336 Third international intersex forum, n 123.
337 Androgen Insensitivity Syndrome Support Group Australia et al, n 124.
338 Public statement of UN and regional human rights experts, n 2.
339 World Health Organization and others, 86 supra, page 15
343 Office of the High Commissioner for Human Rights, n 1 at 2.
Annexes
EXPERT MEETING ON ENDING HUMAN RIGHTS VIOLATIONS AGAINST INTERSEX PERSONS

On 16 and 17 September 2015, the Office of the United Nations Human Rights Commissioner for Human Rights convened an expert group meeting in Geneva on ending human rights violations against intersex persons. The meeting brought together 35 experts from academia, civil society organizations, United Nations agencies and bodies, regional human rights mechanisms, national institutions

Summary

In sessions on human rights norms, experts examined human rights standards and norms and their application to the situation of intersex people by UN, regional and national entities. Experts found that multiple and complementary human rights concepts and frameworks are applicable, including freedom from torture and cruel, degrading and inhuman treatment; violence; harmful practices including female genital mutilation; violations of bodily and mental integrity; autonomy; privacy; free and informed consent; and the right to non-discrimination. Experts identified multiple opportunities through each mechanism and institution to address violations, including in reporting, inquiries, recommendations, thematic reports, statements, letters, individual communications and complaints mechanisms. Participants identified multiple intersectionalities between the rights of intersex people, the rights of the child and the rights of women. The disability framework has powerful elements that resonate with the situation of intersex people and violations faced, though there are some nuances and different perspectives on its application.

Participants also looked at factors influencing harmful medical practice, including surgeries. These range from discriminatory stereotypes, taboos, prejudices and beliefs, and the vulnerable position of young children, to a generalized lack of a human rights approach and absence of safeguards training on respecting fundamental human rights in medical settings, and to nomenclature and medical classifications relating to intersex persons. Participants noted the continuous nature of harm – which can be lifelong, and have deep impact on trajectories over a lifetime, including physical and mental consequences, and also in terms of consequences for education and employment. The use of prenatal interventions and genetic selection was also noted.

In considering the implementation of human rights standards by different national stakeholders, experts examined legislation that protects physical integrity of minors, to anti-discrimination legislation and measures, policies to protect rights within the education system, and measures by national human rights institutions and by other national bodies, including ethics commissions.

Participants looked at work to increase public awareness and public debate, and recognition of violations, and to establish protocols for care and attention that protect the rights to physical integrity, dignity and autonomy of intersex children and adults.

In most places, progress to identify human rights violations has not yet translated into significant or widespread changes in practices in the treatment of intersex adults, children or infants. Indeed, some statistics show an increase in numbers of surgeries. Few court cases have provided remedies, while other court cases have facilitated violations.

All of this progress has been made possible by the work of intersex organizations, yet the meeting heard of the precarious and underfunded nature of this work, without which United Nations, regional and national human rights mechanisms could not address this issue.
Proposals and priorities

Legal guarantees and safeguards

Experts recommended the prohibition of medically-unnecessary non-consensual medical interventions. Legal safeguards were recommended to safeguard the right of children to be heard and protected and ensure that nobody, including parents of underage children, can consent to medically unnecessary cosmetic surgery and other unnecessary medical treatment. Experts recommended that civil and criminal frameworks recognize medically unnecessary non-consensual medical interventions as offences of violence against the person, such as grievous bodily harm. Statutes of limitations barring civil and criminal actions against perpetrators should be extended, as in other cases such as child sexual abuse and asbestosis.

UN, regional and national human rights mechanisms must address harm committed through medically unnecessary non-consensual intervention on intersex individuals under the respective provisions of each treaty and mandate.

Experts recommended capacity building for judicial systems to ensure that intersex people have effective access to justice. Victims of human rights violations are entitled to truth, justice, reparation, rehabilitation and other remedies. In some cases, access to treatment may be reparative.

Regarding birth registration systems, experts recommended that any new legal classifications (such as an X sex or gender marker) should be universally available, and not be specific to an intersex population.

Standards of care and protection in medical settings

Experts recognized that there are objective medical needs associated with intersex bodies, and a need to distinguish bodily diversity from medical necessity (including distinguishing social, cultural and other related “psychosocial” rationales from urgent, physical rationales for medical intervention). Experts found similarities between intersex and other forms of bodily diversity, such as albinism.

Experts identified a need to depathologize intersex traits, and bodily diversity in general. It was recommended that the bodies of intersex persons (including reproductive and hormone producing capacities) must be valued in the same way as those capacities are valued in the bodies of non-intersex persons. Experts agreed that full, free and informed consent must be provided by affected individuals.

Experts identified a need to address a lack of clinical transparency, including secrecy attached to clinical data, practices and guidelines. Violations should be documented and monitored, including in health settings, to ensure that survivors are included and that intersex genital mutilations are adequately addressed.

Experts found it necessary to apply human rights principles to the implementation of medical protocols, and to ensure that children are recognized as subjects of rights, and not objects. It was recommended that human rights principles be applied to medical classification codes relating to intersex traits, including at the international level. Experts suggested that relevant bodies, including the World Health Organization, produce guidelines affirming a human rights approach to intersex issues in medical settings. The development of human rights-based training curricula for health professionals was also recommended.
Experts recommended that parents receive better information, support and counselling, including affirmative, independent peer support. Recognizing the existence of concerns regarding prenatal and genetic selection issues, as well as surgeries and hormonal interventions, experts recommended that standards of care start before birth though affirmative information during pregnancy, and through counselling, and access to peers. Experts agreed that greater transparency regarding clinical practices is required.

**Overcoming discrimination**

Discrimination against intersex people must be prohibited, preferably as a standalone attribute (of sex characteristics), or, at a minimum, through a progressive interpretation of sex.

Experts identified a necessity to link anti-discrimination measures to legislation and medical classifications, and to support for intersex organizations. Experts noted that visibility requires standards, youth participation, role models, campaigns, language, and ownership. More data on employment is needed.

Experts recommended the creation of education guidelines for schools, healthcare and medical practitioners, including on training and bullying and possibly including human rights education in curricula. Diversity education should include bodily diversity, and intersex people need to be portrayed in schoolbooks in a positive manner that affirms human diversity.

**Research, data and implementation**

Experts identified a need to address research issues, tackling issues of funding, a lack of research operating within human rights framework, and a lack of research with intersex leadership. Experts recognized issues of privacy, with examples of good (and poor) practices available, including pitfalls like adding intersex to a question on legal sex classifications.

Experts identified a need to disaggregate “LGBTI” data, with care to distinguish LGB and trans populations and issues from intersex populations and issues, while recognizing that there is overlap between these populations. Experts also identified a need to recognize commonalities with other populations, including people with disabilities, children’s rights, and the rights of women.

On all issues, experts identified a need to push implementation.

Participants included representatives of treaty bodies, special rapporteurs, the Office of the UN High Commissioner for Human Rights, World Health Organization and other UN institutions; regional human rights institutions; intersex, clinical, children’s rights and LGBT civil society organizations; national governments; and biomedical ethics institutions.
UN AND REGIONAL EXPERTS STATEMENT, INTERSEX AWARENESS DAY, 26 OCTOBER 2016


Intersex Awareness Day – Wednesday 26 October

End violence and harmful medical practices on intersex children and adults, UN and regional experts urge.344

(24 October 2016) – Speaking ahead of Intersex Awareness Day on 26 October, a group of United Nations and international human rights experts is calling for an urgent end to human rights violations against intersex children and adults. They urge Governments to prohibit harmful medical practices on intersex children, including unnecessary surgery and treatment without their informed consent, and sterilization.

In countries around the world, intersex infants, children and adolescents are subjected to medically unnecessary surgeries, hormonal treatments and other procedures in an attempt to forcibly change their appearance to be in line with societal expectations about female and male bodies. When, as is frequently the case, these procedures are performed without the full, free and informed consent of the person concerned, they amount to violations of fundamental human rights.

Parents of children with intersex traits often face pressure to agree to such surgeries or treatments on their children. They are rarely informed about alternatives or about the potential negative consequences of the procedures, which are routinely performed despite a lack of medical indication, necessity or urgency. The rationale for these is frequently based on social prejudice, stigma associated with intersex bodies and administrative requirements to assign sex at the moment of birth registration.

Profound negative impacts of these often irreversible procedures have been reported, including permanent infertility, incontinence, loss of sexual sensation, causing life-long pain and severe psychological suffering, including depression and shame linked to attempts to hide and erase intersex traits. In many cases intersex people do not even have access to their own medical records or original birth certificates.

While awareness of the existence and rights of intersex people is slowly growing thanks to the work of intersex human rights defenders, only a handful of countries have taken concrete measures to uphold their rights and protect them from abuses.

States must, as a matter of urgency, prohibit medically unnecessary surgery and procedures on intersex children. They must uphold the autonomy of intersex adults and children and their rights to health, to physical and mental integrity, to live free from violence and harmful practices and to be free from torture and ill-treatment. Intersex children and their parents should be provided with support and counselling, including from peers.

Intersex children and adults should be the only ones who decide whether they wish to modify the appearance of their own bodies – in the case of children, when they are old or mature enough to make an informed decision for themselves. They should have access to support as well as to medical services that respond to their specific health needs and that are based on non-discrimination, informed consent and respect for their fundamental rights. In this connection, it is critical to strengthen the integration of these human rights principles in standards and protocols issued by regulatory and professional bodies.

344 Public statement of UN and regional human rights experts, 2 supra
States should investigate human rights violations against intersex people, hold those found guilty of perpetrating such violations accountable and provide intersex people subjected to abuse with redress and compensation.

Ending these abuses will also require States to raise awareness of the rights of intersex people, to protect them from discrimination on ground of sex characteristics, including in access to health care, education, employment, sports and in obtaining official documents, as well as special protection when they are deprived of liberty. They should also combat the root causes of these violations such as harmful stereotypes, stigma and pathologization and provide training to health professionals and public officials, including legislators, the judiciary and policy-makers.