

# **Report to the Inter-American Commission on Human Rights: Medical Treatment of People with Intersex Conditions as a Human Rights Violation**

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## **I. Introduction**

Americans born with intersex conditions, or variations of sex anatomy, face a wide range of violations to their sexual and reproductive rights, as well as the rights to bodily integrity and individual autonomy. Beginning in infancy and continuing throughout childhood, children with intersex conditions are subject to irreversible sex assignment and involuntary genital normalizing surgery, sterilization, medical display and photography of the genitals, and medical experimentation. In adulthood, and sometimes in childhood, people with intersex conditions may also be denied necessary medical treatment. Moreover, intersex individuals suffer life-long physical and emotional injury as a result of such treatment. These human rights violations often involve tremendous physical and psychological pain and arguably rise to the level of torture or cruel, inhuman, or degrading treatment (CIDT).<sup>†</sup>

The treatment experienced by American intersex people is a violation of the American Convention on Human Rights. The Convention recognizes torture and cruel, inhuman, or degrading treatment (CIDT) as human rights abuses. Under Article V, “(1) Every person has the right to have his physical, mental, and moral integrity respected. (2) No one shall be subjected to torture or to cruel, inhuman, or degrading punishment or treatment.” §1-2. In order to demonstrate why specific medical practices are human rights abuses against intersex people, we have applied Article 16 of the Convention Against Torture (CAT), and interpretations by the European Court of Human Rights and the mandate of the Special Rapporteur on Torture (SRT).

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\* This report drew heavily on the Parallel Report to the 5<sup>th</sup> Periodic Report of the Federal Republic of Germany on the Convention Against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment, by the Association of Intersexual People / XY Women and Humboldt Law Clinic: Human Rights, available at [http://intersex.shadowreport.org/public/Association\\_of\\_Intersexed\\_People-Shadow\\_Report\\_CAT\\_2011.pdf](http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf). We also thank Christina Winship, JD, for extensive drafting and production assistance, and the students and staff at the Georgetown University’s O’Neill Institute for National and Global Health Law, for their research.

† This report was produced in a short time-frame, and is not comprehensive. It focuses on the most egregious abuses affecting people with intersex conditions in medical settings, and on claims that can be readily documented in the medical literature or in official publications. The injuries suffered by intersex people worldwide have not been adequately documented, and additional research is needed in this area to document widespread anecdotal reports of additional harm stemming from torture or CIDT in medical treatment, and to summarize those reports that have been documented.

## **II. What are intersex conditions?**

Intersex conditions, also called differences of sex development (DSD), have been defined by medical sources as congenital conditions that cause atypical development of chromosomal, gonadal and/or anatomical sex. (Hughes 2006) The terms “intersex” and “DSD” are umbrella terms for many different medical conditions, including androgen insensitivity syndrome, virilizing congenital adrenal hyperplasia (CAH), Klinefelter’s syndrome, Turner’s syndrome, hypospadias, bladder exstrophy, and many others. Many children born with intersex conditions have genitals that seem “ambiguous” to caregivers. Others have genitals that seem to be clearly male or clearly female, but are atypical in some way, such as a very large clitoris or a penis that is very small or has a urethra somewhere along the underside of the penis. Others have typical male or female genitals, but they may have atypical sex chromosomes or internal sex organs (such as testes inside the abdomen of a child with female genitals), and/or they may have atypical sex development at puberty. (ISNA 2012) The frequency of intersex births is not well-established, but common estimates are between one in 1,000 and one in 2,000 live births. (Blackless 2000, Phornphutkul 2000)

## **III. Violations experienced by people with intersex conditions in health care settings**

When a child is born with an intersex condition, parents and doctors alike are frequently unsettled by the child’s atypical genitals and the possibility of “gender uncertainty.” There is a great sense of urgency about making a quick gender assignment, despite the fact that from 8.5-20% (or more depending on the specific condition) of these children ultimately reject their gender assignment. (Hughes 2006; Karkazis 2008; Furtado 2012) Genital surgery is commonly performed in the first two years of life, often by six months. (Hughes 2012; Creighton 2012) Removal of internal sex organs is also a common practice. Children with intersex conditions may have medical photographs taken of their genitals and may experience a large number of genital exams throughout childhood, which can be psychologically damaging. (Karkazis 2010, Hughes 2006) Because of their unique conditions, these children are often used as human research subjects, and concerns have been raised about whether standard human research protections have been consistently used. In adulthood, intersex people may have more difficulty accessing needed medical care, and there have been reports of denial of care for discriminatory reasons.

### **A. Irreversible sex assignment and genital normalizing surgery**

While it is widely recognized that there is insufficient data on surgical and sexual outcomes to support any particular recommendation about the timing of genital surgery or to predict gender identity outcomes with confidence in many conditions (Lee 2012; Liao 2012), doctors in the United States, across the Americas, and around the world continue to perform infant genitoplasty in children with intersex conditions. Genital surgery is not necessary for gender assignment, however, and atypical genitals are not in themselves a health issue. (Karkazis 2010)

While there are a few situations where some surgery is necessary for medical reasons, such as to create an opening for urine to exit the body, most procedures commonly performed on children with intersex conditions are cosmetic, not necessary in childhood, and/or done for gender-related social reasons such as “to achieve an unobstructed, sex-typical manner for urination (i.e. standing for males).” (Creighton 2012) Rationales often provided for such surgery for minors include reducing gender confusion for the child and parents, responding to parental concerns that the child be “normal” and accepted, and promoting the child’s social integration and happiness. (Parens 2006; Karkazis 2010) However, evidence that surgery provides these benefits is lacking. (Hughes 2006; Karkazis 2010; Creighton 2012) No studies have linked early genital surgery to successful gender outcome. (Creighton 2012)

In addition to the usual risks of anesthesia and surgery in infancy, genital normalizing surgery carries a number of known risks of harm. Vaginoplasty, a procedure undertaken to create a vaginal opening or to elongate a vagina that is inadequate for sexual intercourse has many risks and complications, including scarring at the introitus and growth of abnormal tissue (“neoplasia”), necessitating repeated intervention. (Hughes 2006) Regular vaginal dilation is often imposed on the child after vaginoplasty. The repeated forcing of a solid object into the vagina of a child has been described as extremely painful, highly traumatic, and comparable to sexual abuse in terms of the patient’s experience. (Shadow Report 2011; Alexander 1997) Clitoral reduction is a cosmetic procedure used to reduce the size of a clitoris that is considered too large. It carries significant risk of loss or impairment of sexual function. “Adult women who have undergone clitoral surgery in infancy report reduced sexual sensation and poorer sexual function when compared to normal controls and also to women with clitoromegaly who had not undergone surgery.” Other risks of genital-normalizing surgery include scarring and incontinence. (Creighton 2012) In one study, of “57 46XY DSD adults who had undergone genital surgery, 47.1% were dissatisfied with functional results, 47.4% with clitoral arousal and 37.5% with overall sex life; 44.2% had sexual anxieties, 70.6% had problems with desire and 56.3% reported dyspareunia [painful intercourse].” (Lee 2012)

Many providers believe that surgical advances have reduced the risk of genital surgery, and that modern techniques may preserve sexual sensation. (Yang 2007) However, any cutting of the genitals carries the risk of harm and nerve damage. (Creighton 2012) Furthermore, surgeons have been confidently announcing improvements in genital normalizing surgery for decades (Kogan 1983; Mollard 1981), without producing meaningful long-term follow-up studies to demonstrate this success. In fact, there is still “much debate but little data on all aspects of clitoral surgery” including where and when it is safe to cut the clitoris and surrounding tissue, and what size and shape of genitals are acceptable. (Creighton 2012; Lee 2012)

Psychological as well as physical harm can result from involuntary genital normalizing surgery. Patient advocacy groups around the world have called for an end to the practice of conducting these surgeries in early childhood (Tamar-Mattis 2006; Karkazis 2008), and there have been numerous reports of patient dissatisfaction. (Creighton 2012) One

recent study of 50 pediatric patients concluded: “The quality of life of pediatric patients with DSDs was impaired to varying degrees following reparative surgery.” (Zhu 2012) Another study found elevated rates of self-harming behavior and suicidal tendencies among intersex people comparable to those among women who have experienced physical or sexual abuse. (Schützmann 2009) The trauma and psychological harm resulting from this practice has been compared to that of female genital mutilation (FGM) and childhood sexual abuse. (Ehrenreich 2005; Alexander 1997)

Furthermore, there are higher rates of gender dysphoria in intersex individuals than the general population. (Karkazis 2010; Furtado 2012) As many as 20% of children with intersex conditions may be forced to undergo irreversible genital surgeries in order to achieve a gendered appearance that ends up being inconsistent with their gender identity. Gender dysphoria has been related to behavioral and emotional problems, with a potential link to increased risk of suicide. (Furtado 2012)

In spite of these risks, genital normalizing surgery remains widespread in the United States for children with intersex conditions. In 2009, for example, the federally-sponsored KIDS Inpatient Database reported 680 hypospadias repairs and 59 instances of “Operations on clitoris, amputation of clitoris, clitoridotomy, [or] female circumcision.” These reported numbers do not include all US hospitals.

Genital normalizing surgery may be done with or without the consent of parents and without taking into consideration the views of the children involved. (High Commissioner for Human Rights, 2011; Wisniewski and Mazur, 2009) Misinformation and directive counseling frequently prevent parents from learning about options for postponing permanent interventions. (Karkazis 2010) Parents often consent to surgery on their children in circumstances where full information is lacking; pressure may be applied by clinicians; or parents themselves may feel discomfort with their child’s bodily difference. (Murphy 2011, Karkazis 2008) Further, ethical and human rights standards dictate that the child’s interests, not parents’, must be the primary consideration in decisions regarding major invasive medical procedures. Postponing surgery until a child is sufficiently mature to make an informed decision has been recommended to ensure the child could participate in decision-making and consent. (Intersex Society of North America; Crouch and Creighton 2007; European Commission 2012; Swiss National Advisory Commission on Biomedical Ethics 2012; Murphy 2011) However, this recommendation has not been widely implemented.

## B. Involuntary sterilization and gonadectomy

People with intersex conditions may be subjected to involuntary sex-assignment treatments as infants or during childhood that, in some cases, terminate or permanently reduce their reproductive capacity. While some intersex people are born infertile, and some retain their fertility after medical treatment, many undergo removal of viable gonads or other internal and external reproductive organs (Hughes 2006; Wisniewski 2009), leaving them with permanent, irreversible infertility and causing severe mental suffering.

Medical procedures which might result in sterility have sometimes been rationalized by the reduction of cancer risk (Hughes 2006). Such treatments are often recommended, however, on the basis of weak evidence and insufficient justification (Hauser 1963; Cools et al 2006, Karkazis 2010; Tamar-Mattis 2012). When sterilizing procedures are imposed on children to address a low or hypothetical risk of cancer, the fertility of intersex people is not being valued as highly as that of non-intersex people. (Tamar-Mattis 2012)

Other rationales for gonadectomy are that it will prevent emergence of undesired (to caregivers) secondary sex characteristics, such as facial hair, or that there will be an unspecified “psychological benefit” to removing structures discordant with sex assignment. (Murphy et al 2011) Such justifications are discriminatory because they would never prompt a procedure that would lead to sterilization in a non-intersex child. Furthermore, where prevention of the emergence of undesired secondary sex characteristics is the goal of gonadectomy, the procedure could be postponed until puberty, at which time the child can have input and it will be clearer whether or not the characteristics are indeed undesired by the patient. If retention of potential fertility causes distressing cross-sex changes at puberty, puberty-suppressing agents are a viable option. (Cohen-Kettenis 2010)

Many doctors also do not see sterilizing surgeries as sterilization if the child would not have been fertile in the mode expected for the assigned gender. For example, one published article says: "At the present time fertility is challenging, but not impossible, for individuals with PAIS raised male. In contrast, fertility is not possible for individuals raised female." (Wisniewski and Mazur 2009) PAIS is a condition in which the child has ambiguous genitals, and has testes that are often functional. There is still controversy and uncertainty about gender assignment in these cases, and it can go either way, depending largely on the doctor's judgment. (Wisniewski and Mazur 2009, Hughes 2006) However, clearly the fertility does not depend on whether the child is raised as a boy or a girl. The authors quoted see fertility as impossible for a child with PAIS raised as female because they assume that raising her as female will include removing her testes. This concept is so entrenched in the medical literature as to go unspoken.

The impact that involuntary sterilization has on the physical health and psychological and social well-being of those individuals who are subject to such violations has been widely recognized. (IG and Others v Slovakia, 2012; VC v Slovakia, 2011; CEDAW Committee Views, 2006; Federal Constitutional Court of Germany, 2011; European Commission, 2012; CRC General Comment 9, 2006; FIGO 2012) Gonadectomy also causes the end of natural hormone production, which prevents the body from changing the way it naturally would have during puberty. Life-long hormone replacement therapy is required for those who have been gonadectomized. (Hughes 2006)

### C. Medical display, genital photography, and excessive genital exams

In addition to the physical and emotional problems that can be caused by surgical intervention, many intersex individuals suffer lasting psychological effects as a result of

repeated genital examinations in childhood. “Repeated examination of the genitalia, including medical photography, may be experienced as deeply shaming. . . . Medical interventions and negative sexual experiences may have fostered symptoms of posttraumatic stress disorder and referral to a qualified mental health professional may be indicated.” (Hughes 2006) While some genital exams are deemed necessary for diagnosis or monitoring of medical conditions, others are done without specific indication, sometimes to satisfy provider curiosity or for purposes of training providers. (Karkazis 2010) Complications and follow-up of genital surgery can make additional exams necessary.

A leading patient advocacy group has likened such procedures to child sexual abuse (CSA):

“[C]hildren with intersex conditions are subjected to repeated genital traumas which are kept secret both within the family and in the culture surrounding it. . . . These children experience their treatment as a form of sexual abuse, and view their parents as having betrayed them by colluding with the medical professionals who injured them. As in CSA, the psychological sequelae of these treatments include depression, suicidal attempts, failure to form intimate bonds, sexual dysfunction, body image disturbance and dissociative patterns.” (Alexander 1997)

#### D. Human experimentation

Several researchers have referred to people with intersex conditions as “experiments of nature,” and indeed this population has attracted a great deal of attention from researchers in the United States interested in sex and gender, even as surgical outcomes and other physical and psychological problems identified by the intersex community have gone largely unexamined.

Bioethicists and physicians have raised alarms about the longstanding practice of giving the powerful steroid dexamethasone to women pregnant with a child who might have virilizing congenital adrenal hyperplasia without adequate clinical trials or the protections normally afforded to human research subjects. The treatment is intended to prevent “masculinizing” effects of the condition, including atypical gender development, “tomboy” behaviors, and lesbianism. While the pregnant women were told for decades that the treatment was the standard of care and had been shown to be “safe and effective,” American researchers were enrolling the prenatally treated children in research studies after treatment, in order to determine if it was in fact safe. (Dreger 2012) Recently a Swedish study of the same treatment was shut down after high rates of birth defects were noted in the treated population, prompting study authors to state, “We find it unacceptable that, globally, fetuses at risk for CAH are still treated prenatally with DEX without follow-up.” (Hirvikoski 2012)

Concerns have also been raised about the activities of an American surgeon and researcher whose published studies recounted attempts to answer questions about genital sensitivity after clitoral surgery by applying a medical vibratory device to the genitals of

conscious girls as young as six years old, and asking them to report on the sensation. Subjects in that study were apparently not afforded human research subject protections before the intervention, and institutional review board approval was only sought for the chart review after the tests had been done. (Dreger 2010, Yang 2007) While a United States Office of Human Research Protection investigation determined that the vibratory tests were part of surgical follow-up and did not constitute research, no other surgeon has reported or recommended this procedure as part of follow-up patient care.

#### E. Denial of needed health care

While children with intersex conditions may suffer from an excess of medical attention and treatment, adults with intersex conditions often have a difficult time finding providers who are educated about their needs. Additionally, some have reported discrimination in health care settings and denial of care once their atypical anatomy is known. Reports have been made to AIC of an adult intersex man who died of vaginal cancer in the United States after being refused treatment at several centers due to discrimination based on him being a man who had a vagina.

### **IV. How medical treatment of people with intersex conditions constitutes human rights abuse**

Many of the violations visited on people with intersex conditions have already been recognized as torture, CIDT, or otherwise as violations of human rights. Various human rights bodies have recognized that coerced sterilization is a violation of human rights constituting torture and CIDT, and that states' obligations to protect persons from such treatment extends into the private sphere, including where such practices are committed by private individuals. (CAT 2007) The UN Special Rapporteur on Torture and the UN Special Rapporteur on Violence against Women have made it clear that FGM is a human rights violation constituting torture and that, from a human rights perspective, the medicalization of FGM – its performance in clinical surroundings – does not make this practice more acceptable. (Report of the Special Rapporteur on Torture; Report of the Special Rapporteur on Violence against Women) No exception has been mentioned for cutting girls' genitals for social or cultural reasons when the girl happens to have an intersex condition. The United Nations Committee on the Rights of the Child has specifically addressed involuntary sterilization of persons with disabilities under the age of 18 as a form of violence, which violates the right of the child to physical integrity and has life-long effects on physical and mental health effects. (General Comment 13, 2011) The Committee has called upon States to prohibit by law the involuntary sterilization of children on grounds of disability (CRC General Comment 9, 2007; CRC, General Comment 13, 2011). Again, no exception has been mentioned for children whose medical condition happens to cause atypical sex characteristics.

The World Health Organization (“WHO”) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” The right to the “highest attainable standard of health” as provided in the Constitution of the WHO is a broad, holistic right that imposes the obligation to offer the greatest degree of



protection to all aspects of an intersex child's well-being. (Constitution of the WHO 1946) In defining reproductive rights, the non-binding Cairo Programme of Action further extends the WHO's wide definition of "health" to apply to "all matters relating to the reproductive system and to its functions and processes." This implies that people "have the capability to reproduce and the freedom to decide if, when, and how often to do so." It represents "the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so... It also includes their right to make all decisions concerning reproduction free of discrimination, coercion and violence..." (Cairo Programme 1995) The WHO also provides the most commonly cited definition of sexual rights, which is the right to "(1) the highest attainable standard of sexual health, including access to sexual and reproductive health care services; (2) seek, receive and impart information related to sexuality; (3) sexuality education; (4) respect for bodily integrity; (5) choose their partner; (6) decide to be sexually active or not; (7) consensual sexual relations; (8) consensual marriage; (9) decide whether or not, and when, to have children; and (10) pursue a satisfying and pleasurable sexual life." (WHO, Gender and Human Rights) Under these broadly accepted definitions, the medical treatment of children with intersex conditions clearly violates their right to health, reproductive rights, and sexual rights. These procedures, undertaken for social and not medical reasons, frequently have negative impact on their physical and mental well-being, permanently limits their ability to make decisions about the functioning of their reproductive systems, and can dramatically impact their sexual rights, including the right to information, respect for bodily integrity, the right to decide whether to be sexually active or not, the right to decide whether to have children, and the right to pursue a satisfying and pleasurable sexual life.

The UN Special Rapporteur on Torture has pointed out: "Whereas a fully justified medical treatment may lead to severe pain or suffering, medical treatments of an intrusive and irreversible nature, when they lack a therapeutic purpose, or aim at correcting or alleviating a disability, may constitute torture and ill-treatment if enforced or administered without the free and informed consent of the person concerned." (SRT 2008) Under these interpretations, the medical practices described above constitute torture or CIDT in violation of Article 1(1) of the Convention Against Torture. Furthermore, the United Nations Special Rapporteur on Torture (SRT) has just issued a statement calling for an end to involuntary genital-normalizing surgeries and other abuses against intersex people.

"Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, 'in an attempt to fix their sex', leaving them with permanent, irreversible infertility and causing severe mental suffering. . . The Special Rapporteur calls upon all States to repeal any law allowing intrusive and irreversible treatments, including forced genital-normalizing surgery, involuntary sterilization, unethical experimentation, [or] medical display ... when enforced or administered without the free and informed consent of the person concerned. He also calls upon them to outlaw forced or coerced sterilization in all circumstances and provide special



protection to individuals belonging to marginalized groups” (SRT 2013)

The analysis below specifically references the CAT’s standards for torture and CIDT, which require that they be intentional and performed for discriminatory and non-medical purposes; performed with state control, custody or consent; cause severe physical and psychological pain or suffering; and involve those who are powerless to refuse. However, it is clear that these medical procedures constitute human rights violations as outlined in other treaties and rulings as well.

#### A. Intent and purpose

The purpose of genital-normalizing surgery is not medical, in that it is not intended to preserve physical health. Instead, the purposes are social and cosmetic. Genital-normalizing surgery is intended to enforce gender norms, and risky medical treatment is imposed as a response to social stigma. Doctors and other healthcare personnel who perform, participate in, and approve these procedures generally believe that what they are doing is best for the child. However, determining intent and purpose do not require a subjective inquiry into the motivation of the perpetrators, but rather an objective determination under the circumstances. (CAT 2007) The Special Rapporteur on Torture has pointed out that intent can be inferred where the act had a specific purpose, such as where a person has been discriminated against on the basis of disability. (SRT 2008) The Rapporteur emphasizes this in the context of medical treatment, where such discriminations are often “masked as ‘good intentions’ on the part of health professionals.” (SRT 2008)

Clearly, the actions of the doctors in conducting genital-normalizing surgery, sterilizing procedures, genital exams, medical display and medical experimentation are intentionally performed. Promoters of these procedures are aware of the severe consequences for patients. The physical and mental suffering caused by cosmetic clitoral surgery and other genitoplasty, vaginal dilation, loss of fertility, and dependency on hormone substitution is well-established in medical literature, as noted above. The psychological suffering caused by excessive genital exams and photography is also widely recognized in the field, as demonstrated by its inclusion in an international consensus statement on treatment of intersex conditions. (Hughes 2006)

The medical treatment of children with intersex conditions is done with discriminatory purposes, in that these children undergo cosmetic genital-normalizing surgery so that their bodies conform to dominant ideas of what constitutes a ‘male’ or ‘female’ body. (Association of Intersexual People / XY Women 2011) These surgeries are acknowledged in the medical literature to be cosmetic and intended to ensure the child develops with conformity to sex and gender norms. (Creighton 2012) Enabling heterosexual intercourse is often an important goal (Creighton 2012), and in doing so surgeons may eradicate options for other forms of sexual expression. The focus of the limited outcome studies that are available on genital-normalizing surgeries belie their purpose, as most emphasize marriage rates, heterosexual intercourse, gendered behavior, and genital appearance. (Liao 2012, Wisniewski 2009) Very few focus on psychological

well-being, patient satisfaction, or sexual pleasure or function. (Liao 2012, Cohen-Kettenis 2010) The goals and mode of treatment also differ according to what sex the doctors think the patient should be. In children assigned as girls, female fertility is prioritized even if treatment may damage sexual function and enjoyment. In children assigned as boys, the ability to penetrate a partner and stand to urinate is considered crucial; if the phallus is considered “inadequate” for these functions, the child may be assigned female and male fertility will be eradicated. (Tamar-Mattis 2012, Karkazis 2008, Hughes 2006)

In considering intent, it is particularly noteworthy that doctors who perform genital-normalizing surgery are well aware that many of the children they operate on will ultimately reject their assigned sex. For example, one published review recognized that 10% of CAH cases have been shown to develop gender dysphoria, but concluded that “assigning female gender and performing premature surgery is safe in the majority of cases.” (Furtado 2012) In other words, the authors support removing or reducing the phallosclitoris and performing irreversible feminizing genitoplasty on infants with CAH, in spite of the fact that one in 10 of those infants will grow to identify as male. These authors further recognize rates of gender dysphoria as high as 8.5-20% in intersex conditions generally, yet maintain that early surgery remains safe. (Furtado 2012) A recent international consensus statement on treatment of intersex conditions reaches similar conclusions, even while recognizing rates of gender change as high as 40% in some conditions. (Hughes 2006)

Doctors are also aware that there is usually no medical necessity for genital-normalizing surgery, and offer social justifications, believing that the abuse they commit is necessary to prevent future discrimination against children with bodies that challenge the norm. However, just as it is a violation of the child’s human rights to address parental discomfort through surgery on the child, it is a violation to address societal discomfort by the same means. This is discrimination on the basis of social stigma. The unavoidable pain of surgery and the high risk of severe lifelong physical and mental suffering – from loss of sexual sensation and function, pain caused by scarring, infertility, castration, violation of bodily integrity, and irreversible surgical assignment to the wrong sex – would never be accepted by doctors or parents if the child did not have an intersex body. The belief that such high risk is acceptable for a child with an intersex condition is the discriminatory attitude that drives these human rights violations. The fact that there is no medical justification for the ill-treatment means that good intentions cannot prevent the treatment from constituting torture.

Where medical justifications are offered for specific procedures, such as to prevent risk of cancer or to prevent future urinary tract infections, the risk/benefit analysis should be the same for children with intersex conditions as it would be for other children. So, for example, no ethical doctor would suggest removing a healthy infant girl’s breast buds to protect her from breast cancer in the future. Similarly, it is not ethical to remove non-malignant gonads from a child with an intersex condition to protect against a low or hypothetical risk of cancer, especially where monitoring is an option. (Hughes 2006) Using an extreme and invasive procedure to address a minor or hypothetical risk is

discrimination if the risk would not be considered to justify such treatment in a non-intersex person.

Government bodies considering the question of genital-normalizing surgery have noted the potential for discrimination and human rights violations. The Swiss National Advisory Commission on Biomedical Ethics recently found:

“An irreversible sex assignment intervention involving harmful physical and psychological consequences cannot be justified on the grounds that the family, school or social environment has difficulty in accepting the child’s natural physical characteristics. The harmful consequences may include, for example, loss of fertility and sexual sensitivity, chronic pain, or pain associated with dilation (bougienage) of a surgically created vagina, with traumatizing effects for the child. If such interventions are performed solely with a view to integration of the child into its family and social environment, then they run counter to the child’s welfare.” (Swiss National Advisory Commission on Biomedical Ethics 2012)

The Colombian Constitutional Court, in considering a case involving genital-normalizing surgery on a child, opined that some “parents who consent to surgery may actually be discriminating against their own children.” (Tamar-Mattis 2006)

#### B. State control, custody, or consent

The Committee Against Torture has noted that state parties must make sure that with respect to the Convention, their laws are in practice applied to all persons, ‘regardless of ... gender, sexual orientation, transgender identity, mental or other disability, health status, ...’. This includes fully prosecuting and punishing all acts of violence and abuse against these individuals and implementing positive prevention and protection measures. (CAT 2007) The Special Rapporteur on Torture has emphasized that the obligation to prevent torture extends “to doctors, health professionals and social workers, including those working in private hospitals [or] other institutions.” (SRT 2008) This indicates that people with intersex conditions must be treated without discrimination based on their perceived sex or gender difference or physical condition, and that doctors in private as well as state-run medical facilities have the responsibility to protect them from torture and CIDT.

In the case of FGM, a procedure not dissimilar in its particulars and in its social justification to the genital surgery endured by children with intersex conditions, the SRT has specifically pointed out that where this is performed in private clinics and physicians carrying out the procedure are not being prosecuted, the State de facto consents to the practice and is therefore accountable. (SRT 2008) We are unaware of any nation that prosecutes its own FGM laws in cases where the girl undergoing clitoral cutting has an intersex condition. Laws protecting people from involuntary sterilization are also not being enforced where the person being sterilized is a child with an intersex condition. (Tamar-Mattis 2006, 2012)

### C. Infliction of severe pain or suffering

The UN Special Rapporteur on Torture has pointed out that children are more vulnerable to the effects of torture as they are in the critical stages of physical and psychological development where they may suffer graver consequences than similarly ill-treated adults. (SRT 1996) The medical interventions imposed on children with intersex conditions may be all the more terrifying to them because they are unable to understand what is happening or to resist. This includes genital exams, the repeated catheterization that often follows complications of genital surgery, and vaginal dilation, in addition to the severe pain and suffering resulting from genital surgery and sterilization as outlined above. Young children may be unable to distinguish these procedures from intentional sexual abuse. Older children, having grown up with repeated genital interventions and exams, may find themselves unable to voice resistance. The pain and suffering experienced by these children is comparable to that of rape or sexual abuse (Alexander 1997), or of some forms of FGM. (Ehrenreich 2005)

In addition, genital-normalizing surgery and gonadectomy cause the physical and psychological pain attendant to any major surgery, along with specific long-term problems. These include genital scarring and pain, diminished or absent sexual function, incontinence, vaginal stenosis, urinary tract fistulas, dyspareunia (painful sexual intercourse), depression, poor body image, dissociation, social anxiety, suicidal ideation, shame, self-loathing, difficulty with trust and intimacy, post-traumatic stress disorder, and the wide-ranging consequences of a surgical attempt at sex assignment that often fails and cannot be undone. (SFHRC 2004, Creighton 2012, Lee 2012) Many intersex people report a level of trauma and fear of doctors that renders them unable to access even ordinary medical care. (SFHRC 2004, Karkazis 2008) The pain and suffering associated with medical treatment of intersex conditions clearly rises to the level of other acts considered to be torture or CIDT.

### D. Powerlessness of the victim

As with children undergoing female genital mutilation (FGM), children with intersex conditions undergoing surgery at an early age are in a situation of powerlessness, as they are under the complete control of their parents and medical personnel and have no means of resistance. The parents themselves also often report a sense of powerlessness. (Karkazis 2008) Soon after the birth of a child with an atypical body, they are quickly confronted with an alleged need for quick medical intervention. They may be threatened with scenarios of ostracism and cancer, and are pushed to make decisions that will affect their child forever, usually without complete information about the limitations and risks of these procedures or the option to postpone decisions until the child can participate. (Karkazis 2008, 2010)

## **V. Conclusion and Recommendations**

Intersex people suffer significant violations of their human rights to dignity, bodily integrity, control of reproduction, and privacy in medical settings. These violations

include cosmetic genital-normalizing surgery in childhood, involuntary sterilization, excessive genital exams and medical display, human experimentation, and denial of needed medical care. We have argued that such treatment meets the threshold requirements of intent and discriminatory purpose, state control, pain and suffering, and powerlessness of the victim to constitute torture under Article 1 of the Convention Against Torture, and that it constitutes human rights violations of human rights as recognized in multiple other treaties.

Even if it is considered that the treatment intersex people suffer does not meet the severity threshold of Article 1 of the CAT, however, it certainly meets the threshold of Article V §1 of the American Convention on Human Rights. Article V §1 states that “Every person has the right to have his physical, mental, and moral integrity respected.” At the very least, the above enumerated practices are an egregious trespass against the physical and mental integrity of intersex individuals.

The IACHR, and its LGBTI Unit, is to be commended for its willingness to include intersex rights within its scope, and for offering this forum to hear from the intersex community. Beyond merely including intersex persons and issues in hearings and events, it is necessary to recognize that intersex individuals and in particular intersex children face unique medical, social and human rights issues distinct from those of LGBT individuals, and suffer may a wide range of injustices from birth through to adulthood. We look forward to further action resulting from these hearings, that should include concrete steps to address the specific human rights abuses prioritized by the intersex community.

For the Inter-American Commission to **recognize that the childhood genital-normalizing surgery, involuntary sterilization, unethical experimentation, medical display, and denial of medical treatment experienced by intersex people rises to the level of torture, CIDT, and is therefore a human rights violation**, would be an enormous step forward in ending these abuses. Currently these treatments are widely recognized as “controversial” and are promulgated by a small community of specialist providers. Non-surgeons on treatment teams may feel uncomfortable challenging surgical decisions. (Creighton 2012) Recognizing these procedures as torture and CIDT would give support to the many providers who already question them.

In its concluding observations from its report on Germany, the Committee Against Torture recommended that **informed consent should be ensured in medical and surgical treatment of intersex conditions**, that **instances of such treatment without consent should be investigated**, **redress to victims of such treatment should be provided**, and that **medical and psychological professionals should be educated and trained about sexual and related biological and physical diversity**, and that **professionals should properly inform patients and their parents of consequences of unnecessary interventions for intersex people**. (CAT 2011) We support all of these recommendations for all signatory states of the Inter-American Commission, and also recommend that **states enforce laws prohibiting involuntary sterilization and FGM in cases involving children with intersex conditions**.

We also adopt the following (adapted) recommendations for all signatory states from the Association of Intersexual People / XY Women. (Shadow Report 2011)

1. Prevent torture and cruel, inhuman or degrading treatment (Art. 1, 2, 16 CAT):
  - a. **Cease all gonadectomies on children** unless there is clear and reliable medical evidence of a severe risk of tumor development, both in public and in private settings.
  - b. **Cease all cosmetic surgery on children's genitals**, both in public and in private settings.
  - c. **Provide for truly informed consent** of parents, young and adult patients, both in public and in private settings: Provide full information, orally and in writing, on the quantity and quality of the evidence suggesting the treatment; on the alternatives to the suggested intervention, including non-intervention, and their likely effects; on necessary follow-up treatment such as hormone substitution for gonadectomy or dilation for vaginoplasty, including physical and psychological side-effects and long- term effects; on the legal situation regarding parental consent including the child's right to an open future; on the existence of support groups.
  - d. **Avoid situations of powerlessness** in hospitals, both public and private: Make sure parents know that there is no time pressure on a decision except in cases of true medical emergency; allow for parents to adapt to the condition of their child; provide financial and structural support for intersex self-help groups and outreach activities to young parents in hospitals.
2. Ensure that education and information regarding the prohibition against torture are fully included in the training of medical personnel (Art. 10 CAT):
  - a. Include **specific vocational training** of medical professionals on intersex conditions in all medical disciplines.
  - b. **Ensure that all medical professionals know that medically unjustified gonadectomy and feminising surgery amount to the infliction of torture or CIDT** and constitute a punishable offense.
3. Ensure that any intersex person who alleges they have been subjected to torture has the right to complain to, and to have their case promptly and impartially examined by, competent authorities (Art. 13 CAT) and ensure in the legal system that an intersex victim of an act of torture obtains redress and has an enforceable right to fair and adequate compensation, including the means for as full rehabilitation as possible (Art. 14 CAT):
  - a. Ensure each individual's **full access to the entirety of their medical files** in practice.
  - b. Review the specific problems encountered by intersex people in the pursuit of their rights with respect to the **statute of limitations**.
  - c. Establish an **aid and compensation fund** for affected persons.
  - d. Provide **access to medical supply without discrimination**, including hormone substitution corresponding with the individual's gender identity.

Finally, **we adopt the following recommendations** from the Swiss National Advisory

Commission on Biomedical Ethics (2012):

3. The following basic principle should apply to the management of DSD: on ethical and legal grounds, all (non-trivial) sex assignment treatment decisions which have irreversible consequences but can be deferred should not be taken until the person to be treated can decide for him/ herself. This includes genital surgery and the removal of gonads, unless there is an urgent medical indication for these interventions (e.g. increased risk of cancer). Exceptions to the general rule would be cases where a medical intervention is urgently required to prevent severe damage to the patient's body or health.

12. There should be a legal review of the liability implications of unlawful interventions in childhood, and of the associated limitation periods. Questions of criminal law, such as the applicability of offences of assault ... and the prohibition on genital mutilation ... should also be investigated.

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