

Report to the International Lesbian, Gay, Bisexual, Trans and Intersex Association Universal Periodic Review: Medical Treatment of People with Intersex Conditions

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I. Introduction

Americans born with intersex conditions face a wide range of violations of their sexual and reproductive rights, as well as rights to bodily integrity and individual autonomy. In infancy and 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. Intersex individuals suffer life-long physical and emotional injury as a result of such treatment.

Various human rights bodies have recognized that the medical treatment of people with intersex conditions rises to the level of human rights violations. The World Health Organization (WHO) has called for the elimination of involuntary sterilization, noting that sterilization without informed consent has been described as a violation of fundamental human rights. (WHO 2014) WHO recognizes that “[i]ntersex persons, in particular, have been subjected to cosmetic and other non-medically necessary surgery in infancy, leading to sterility, without informed consent of either the person in question or their parents or guardians.” (WHO 2014) The United Nations Committee on the Rights of Persons with Disabilities (CRPD) has called for data collection on the frequency of genital mutilation and forced sterilization of intersex children, and a plan to end these practices, in Germany. (CRPD 2014) The United Nations Special Rapporteur on Torture (SRT) has also called for an end to the 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)

Despite this international outcry, these procedures are still occurring in the US today.

* This report drew heavily on the Parallel Report to the 5th 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. We also thank Christina Winship, JD, and Courtney Fraser 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.

II. Violations experienced by people with intersex conditions in health care settings

A. Irreversible sex assignment and genital normalizing surgery

When a child is born with an intersex condition, parents and doctors are often unsettled by the child's atypical genitals and the possibility of "gender uncertainty." Due to a sense of urgency about making a gender assignment, genital "normalizing" surgery commonly occurs in the first two years of life, often by six months. Medical literature admits that these surgeries are cosmetic and intended to ensure gender-normative behavior, such as standing to urinate in children assigned as boys. (Creighton 2012) Other motivations include addressing parental concerns that the child be "normal" and promoting social integration and happiness. However, evidence that surgery provides these benefits is lacking. In fact, genital normalizing surgery carries known risks of harm. Vaginoplasty may cause scarring and abnormal tissue growth, requiring repeated intervention. Vaginal stenosis, incontinence, and urinary tract fistulas may also develop. Clitoral reduction carries a significant risk of loss of sexual function and sensation. While clitoral reduction fits the definition of female genital mutilation (FGM), the US fails to enforce its FGM laws when the girl undergoing clitoral cutting has an intersex condition. The SRT has pointed out that where FGM is performed in private clinics and physicians carrying out the procedure are not prosecuted, the State de facto consents to the practice and is therefore accountable. (SRT 2008) AIC is currently planning a project to enforce FGM laws to protect intersex children subject to clitoral reduction surgeries in the US.

Genital normalizing surgery risks psychological as well as physical harm, including depression, poor body image, dissociation, social anxiety, suicidal ideation, shame, self-loathing, difficulty with trust and intimacy, and post-traumatic stress disorder. (SFHRC 2004) Patient advocacy groups have called for an end to these early childhood surgeries, citing numerous reports of patient dissatisfaction. In a 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) Rates of self-harming behavior and suicidal tendencies among intersex people are comparable to those among women who have experienced physical or sexual abuse. Many intersex people report a level of trauma and fear of doctors that renders them unable to access even ordinary medical care. (SFHRC 2004)

Lastly, intersex individuals show elevated rates of gender dysphoria. As many as 20% of children with intersex conditions suffer irreversible surgery that creates a gendered appearance ultimately inconsistent with their gender identity. Egregiously, doctors who perform genital-normalizing surgery are well aware that many of their patients will reject their assigned sex. One review recognized that 10% of congenital adrenal hyperplasia (CAH) cases develop gender dysphoria, but still concluded that "assigning female gender and performing premature surgery is safe in the majority of cases." (Furtado 2012) In other words, the authors support reducing or removing 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) An 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)

Genital normalizing surgery may be done without parental consent or consideration of the child's views. (HCHR 2011) Misinformation and pressure by clinicians often prevent parents from learning of options to postpone permanent intervention. To ensure that the child participates in decision-making, bodies such as the European Commission (2012) and the Swiss National Advisory Commission on Biomedical Ethics (2012) recommend postponing surgery until a child is sufficiently mature to make an informed decision. However, this recommendation has not been widely implemented, and genital normalizing surgery remains widespread in the US 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 reports do not include all US hospitals.

B. Involuntary sterilization and gonadectomy

In some cases, sex-assignment surgery also removes viable gonads or other reproductive organs, terminating or permanently reducing reproductive capacity. The impact of involuntary sterilization on health and well-being has been widely recognized. (European Commission 2012) Like FGM laws, US laws prohibiting involuntary sterilization are also not enforced where the person being sterilized is a child with an intersex condition.

Medical procedures that may result in sterility are sometimes rationalized by reducing the risk of cancer. Often, however, such treatment is recommended based on weak evidence and insufficient justification. For sterilizing procedures, the risk/benefit analysis should be the same for children with intersex conditions as it would be for other children. The lightness with which sterilizing procedures are imposed on intersex children shows that the fertility of intersex people is not being valued as highly as that of non-intersex people.

Gonadectomy also ends natural hormone production, necessitating life-long hormone replacement therapy. Where gonadectomy would aim to prevent the emergence of secondary sex characteristics, it could be postponed until puberty. If at that time the emerging characteristics distress the patient, puberty-suppressing agents are an option.

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

Many intersex individuals suffer lasting psychological effects as a result of repeated genital examinations and/or medical photography in childhood, which can be "experienced as deeply shaming" and may lead to symptoms of PTSD. (Hughes 2006) While some genital exams are necessary for medical diagnosis or monitoring, others are done without specific indication, sometimes to satisfy provider curiosity. 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

When people with intersex conditions become the subjects of research, adequate protections are not always in place. For example, dexamethasone has long been given to women pregnant with a child who might have virilizing CAH to prevent “masculinizing” effects. While women were told for decades that this was safe, US researchers were enrolling prenatally treated children in studies *after* treatment to determine its safety, and a Swedish study of the same treatment was shut down due to high rates of birth defects. Concerns have also been raised about an American surgeon who attempted to investigate genital sensitivity after clitoral surgery by applying a medical vibratory device to the genitals of girls as young as six years old, asking them to report on the sensation. The girls were not afforded human research subject protections, and institutional review board approval was only sought after the tests had been done. (Yang 2007)

E. Denial of needed health care

While children with intersex conditions suffer from an excess of medical attention, adults with intersex conditions often have difficulty finding providers who are educated about their needs. Some have even reported discrimination and denial of care based on their atypical anatomy. For example, AIC is aware of an adult intersex man who died of vaginal cancer in the US after several centers refused to treat a man who had a vagina.

III. Conclusion and Recommendations

Intersex people in the US suffer significant harm as a result of genital-normalizing surgery in childhood, involuntary sterilization, excessive genital exams and medical display, human experimentation, and denial of needed medical care. Such treatment constitutes a violation of human rights as recognized by multiple international bodies.

Accordingly, we make the following recommendations to address the plight of intersex individuals in the US:

- That medical professionals undergo specific training on intersex conditions, including the physical and psychological harm attendant to genital normalizing surgery, sterilization, and excessive genital exams and medical display;
- That, with respect to (1) all cosmetic surgery on children’s genitals and (2) all gonadectomies on children that are not justified by risks as strong as what would be required to perform a similar procedure on a non-intersex child, medical professionals postpone such procedures until the patient is old enough to meaningfully participate in the decision-making process;
- That medical professionals only carry out the described procedures when the patient and parents have been thoroughly informed of the risks (physical and psychological) and alternatives, and have then given their informed consent;
- That medical professionals ensure proper human subjects research protections are in place prior to any research on people with intersex conditions;

- That enforcement agencies investigate possible violations of, and take action to enforce, laws prohibiting FGM, involuntary sterilization, and unethical human subjects research to protect children with intersex conditions; and
- That US courts recognize genital normalizing surgery and involuntary sterilization performed on intersex children as violations of their federal civil rights,[†] and offer intersex plaintiffs comprehensive remedies for these harms.

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[†] In August 2014, a U.S. District Judge for the Charleston Division of South Carolina denied a motion to dismiss just such a claim in AIC’s case, *M.C. v. Aaronson*. The decision is currently being appealed.