

MEDICAL TREATMENT OF PEOPLE WITH INTERSEX CONDITIONS AS TORTURE AND CRUEL, INHUMAN, OR DEGRADING TREATMENT OR PUNISHMENT

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Abstract

People worldwide 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 have been found to rise to the level of torture or cruel, inhumane, or degrading treatment. We offer recommendations for states working to address torture and inhuman treatment in medical settings.

Introduction

People worldwide 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 have been found to rise to the level of torture or cruel, inhumane, or degrading treatment (“CIDT”).

This report 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

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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, as well as in other settings, and to summarize those reports that have been documented.

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.¹ 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, 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.² 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.³

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.**⁴ Genital surgery is commonly performed in the first two years of life, often by six months.⁵ 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

¹ IA Hughes et al., *Consensus statement on management of intersex disorders*, 91 ARCHIVES OF DISEASE IN CHILDHOOD 554-63 (2006).

² Intersex Society of North America. *Intersex Conditions*, <http://www.isna.org/faq/conditions>, accessed Dec. 7, 2012. *Shifting the paradigm of intersex treatment*, <http://www.isna.org/compare>, accessed September 27, 2012.

³ M Blackless et al., *How Sexually Dimorphic Are We? Review and Synthesis*, 12 Am. J. of Human Biology 151-166 (2000); C Phornphutkul, et al., *Gender Self-Reassignment in an XY Adolescent Female Born With Ambiguous Genitalia*, 106 PEDIATRICS 135 (2000).

⁴ K KARKAZIS, *FIXING SEX: INTERSEX, MEDICAL AUTHORITY, AND LIVED EXPERIENCE* (2008); IA Hughes et al., *supra* note 2; P.S. Furtado et al., *Gender dysphoria associated with disorders of sex development*, NAT. REV. UROL. (2012); doi:10.1038/nrurol.2012.182.

⁵ S Creighton, et al., *Timing and nature of reconstructive surgery for disorders of sex development e Introduction*, JOURNAL OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.10.001>; IA Hughes et al., *supra* note 2.

genital exams throughout childhood, which can be psychologically damaging.⁶ 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.

1. Irreversible Sex Assignment and Genital Normalizing Surgery

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.⁷ Nonetheless, doctors 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.⁸

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).”⁹ 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.¹⁰ However, evidence that surgery provides these benefits is lacking.¹¹ No studies have linked early genital surgery to successful gender outcome.¹²

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.¹³ 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

⁶ K Karkazis, A Kon & A Tamar-Mattis, Shared Decision-Making and Children with DSD, 23 J. of Pediatric Endocrinology and Metabolism 789-806 (2010); IA Hughes et al., *supra* note 2.

⁷ P Lee, et al., *Review of recent outcome data of disorders of sex development (DSD): Emphasis on surgical and sexual outcomes*, J. OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.10.017>; L-M Liao et al., *Determinant factors of gender identity: A commentary*, J. OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.09.009>.

⁸ K Karkazis, A Kon & A Tamar-Mattis, *supra* note 7.

⁹ S Creighton, et al., *Timing and nature of reconstructive surgery for disorders of sex development e Introduction*, JOURNAL OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.10.001>.

¹⁰ SURGICALLY SHAPING CHILDREN: TECHNOLOGY, ETHICS AND THE PURSUIT OF NORMALITY (E Parens, ed., 2006); K Karkazis, A Kon & A Tamar-Mattis, *supra* note 7.

¹¹ S Creighton, et al., *supra* note 6; IA Hughes et al., *supra* note 2.

¹² S Creighton, et al., *supra* note 6; K Karkazis, A Kon & A Tamar-Mattis, *supra* note 7.

¹³ IA Hughes et al., *supra* note 2.

painful, highly traumatic, and comparable to sexual abuse in terms of the patient's experience.¹⁴ 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.¹⁵ 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]."¹⁶

Many providers believe that surgical advances have reduced the risk of genital surgery, and that modern techniques may preserve sexual sensation.¹⁷ However, any cutting of the genitals carries the risk of harm and nerve damage.¹⁸ Furthermore, surgeons have been confidently announcing improvements in genital normalizing surgery for decades,¹⁹ 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.²⁰

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 childhood²¹ and there have been numerous reports of patient dissatisfaction. 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."²² Another study found elevated rates of self-

¹⁴ T. Alexander, *The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse*, Intersex Soc. of North Am. (1997), <http://www.isna.org/articles/analog>; Association of Intersexual People, *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* (2011), http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf.

¹⁵ S Creighton, et al., *Timing and nature of reconstructive surgery for disorders of sex development e Introduction*, JOURNAL OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.10.001>.

¹⁶ P Lee, et al., *Review of recent outcome data of disorders of sex development (DSD): Emphasis on surgical and sexual outcomes*, J. OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.10.017>.

¹⁷ J Yang & D Poppas, *Nerve Sparing Ventral Clitoroplasty: Analysis of Clitoral Sensitivity and Viability*, 178 J. OF UROLOGY 1598-1601 (2007).

¹⁸ S Creighton, et al., *supra* note 6.

¹⁹ SJ Kogan, et al., *Subtunical total reduction clitoroplasty: a safe modification of existing techniques*, 130 J. UROLOGY (1983); P Mollard et al., *Clitoroplasty in intersex: a new technique*, 53 BRITISH J. UROL (1981).

²⁰ S Creighton, et al., *supra* note 6; P Lee, et al., *Review of recent outcome data of disorders of sex development (DSD): Emphasis on surgical and sexual outcomes*, J. OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpuro.2012.10.017>.

²¹ K KARKAZIS, *supra* note 5.

²² D Zhu et al., *Quality Of Life Evaluation In Juveniles With Disorders Of Sexual Development*,

harming behavior and suicidal tendencies among intersex people comparable to those among women who have experienced physical or sexual abuse.²³ The trauma and psychological harm resulting from this practice has been compared to that of female genital mutilation (“FGM”) and childhood sexual abuse.²⁴

Furthermore, there are higher rates of gender dysphoria in intersex individuals than the general population.²⁵ 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.²⁶

In spite of these risks, genital normalizing surgery remains widespread around the world for children with intersex conditions. In 2009, for example, the United States’ federally-sponsored KIDS Inpatient Database reported 680 hypospadias repairs and 59 instances of “Operations on clitoris, amputation of clitoris, clitoridotomy, [or] female circumcision.”²⁷ In regions with less access to up-to-date medical treatment, genital normalizing surgery is still practiced, although it may not be provided until a later age if discovery or diagnosis is delayed. In such cases, physician-imposed gender reassignment at a late age has been reported.²⁸

Some specialists have claimed that those who protest their involuntary genital-normalizing surgery are in the minority, and that there is a “silent majority” of patients who are glad of the treatment they received. However, not one such person has ever come forward publicly despite investigations by ethics committees, human rights bodies, and media around the world. The limited follow-up studies that do exist continue to demonstrate high rates of gender dissatisfaction, sexual dysfunction, and surgical complication among patients who have had involuntary childhood genital-normalizing surgery. Even fewer studies exist of intersex people who have not had genital-normalizing surgery, and no studies have demonstrated that growing up with atypical genitals causes any harm.

²⁸ PEDIATRIC SURG INT’L 1119-23.(2012); S Creighton, et al., *Timing and nature of reconstructive surgery for disorders of sex development e Introduction*, JOURNAL OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpurol.2012.10.001>.

²³ Schützmann et al., *Psychological distress, suicidal tendencies, and self-harming behaviour in adult persons with different forms of intersexuality*, 38 ARCH SEX BEHAV. 16-33 (2009).

²⁴ Alexander, *supra* note 15; N Ehrenreich, *Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of “Cultural Practices,”* 40 HARV. C.R. – C.L. L. REV. 71 (2005).

²⁵ K Karkazis, A Kon & A Tamar-Mattis, *supra* note 7; P.S. Furtado et al., *Gender dysphoria associated with disorders of sex development*, NAT. REV. UROL. (2012); doi:10.1038/nrurol.2012.182.

²⁶ P.S. Furtado et al., *Gender dysphoria associated with disorders of sex development*, NAT. REV. UROL. (2012); doi:10.1038/nrurol.2012.182.

²⁷ *KIDS Inpatient Database*, AGENCY FOR HEALTHCARE RESEARCH AND QUALITY: UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES, <http://hcupnet.ahrq.gov/> (These reported numbers do not include all US hospitals.)

²⁸ OD Osifo & TI Amusan, *Female Children with Ambiguous Genitalia in Awareness-Poor Subregion*, 13 African Journal of Reproductive Health 130 (2009).

Genital normalizing surgery may be done with or without the consent of parents and without taking into consideration the views of the children involved.²⁹ Misinformation and directive counseling frequently prevent parents from learning about options for postponing permanent interventions.³⁰ 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.³¹ 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.**³² However, this recommendation has not been widely implemented.

2. 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,³³ 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.³⁴ Such treatments are often recommended, however, on the basis of weak evidence and insufficient justification.³⁵ When sterilizing

²⁹ A Wisniewski & T Mazur, *46, XY DSD with female or ambiguous external genitalia at birth due to Androgen Insensitivity Syndrome, 5-Reductase-2 Deficiency, or 17-Hydroxysteroid Dehydrogenase Deficiency: a review of quality of life outcomes*. INT'L J. OF PEDIATRIC ENDOCRINOLOGY (2009); High Commissioner for Human Rights, *Annual Report to the UN General Assembly: Discriminatory laws and practices and acts of violence against individuals based on their sexual orientation and gender identity* (2011).

³⁰ K Karkazis, A Kon & A Tamar-Mattis, *supra* note 7.

³¹ K KARKAZIS, *supra* note 5; C Murphy et al., *Ambiguous genitalia in the newborn: an overview and teaching tool*, 24 J. PEDIATR ADOLESCENT GYNECOL 236-250 (2011).

³² NS Crouch & SM Creighton, *Long-Term Functional Outcomes In Female Genital Reconstruction In Childhood*, 100 BJU INT'L 403-7 (2007); C Murphy et al., *Ambiguous genitalia in the newborn: an overview and teaching tool*, 24 J. PEDIATR ADOLESCENT GYNECOL 236-250 (2011); Swiss National Advisory Commission on Biomedical Ethics, *On the management of differences of sex development: Ethical issues relating to "intersexuality"*, Opinion No. 20/2012 (2012); Intersex Society of North America, *Intersex Conditions*, <http://www.isna.org/faq/conditions>, accessed Dec. 7, 2012. *Shifting the paradigm of intersex treatment*, <http://www.isna.org/compare>, accessed September 27, 2012; European Commission, Directorate-General for Justice, *Trans and intersex people, Discrimination on the grounds of sex, gender identity, and gender expression* (2012).

³³ A Wisniewski & T Mazur, *supra* note 30; IA Hughes et al., *supra* note 2.

³⁴ IA Hughes et al., *supra* note 2.

³⁵ M Cools et al., *Germ Cell Tumors In The Intersex Gonad: Old Paths, New Directions, Moving Frontiers*, 27 Endocrine Reviews 468-484 (2006); A Tamar-Mattis, *Sterilization and minors with intersex conditions in California law*, 3 CAL. L. REV. CIRCUIT 126-135 (2012); K Karkazis, A Kon & A Tamar-Mattis, *supra* note 7; GA Hauser, *Testicular feminization*, in *Intersexuality* 255-276 (C Overzier ed., 1966).

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.³⁶

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.³⁷ Such justifications are discriminatory because they would never prompt a procedure that would lead to sterilization in a non-intersex child. Furthermore, where the prevention 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.³⁸

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."³⁹ 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.⁴⁰ 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. 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.⁴¹

3. 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

³⁶ A Tamar-Mattis, *Sterilization and minors with intersex conditions in California law*, 3 CAL. L. REV. CIRCUIT 126-135 (2012).

³⁷ C Murphy et al., *Ambiguous genitalia in the newborn: an overview and teaching tool*, 24 J. PEDIATR ADOLESCENT GYNECOL 236-250 (2011).

³⁸ PT Cohen-Kettenis, *Psychosocial And Psychosexual Aspects Of Disorders Of Sex Development*, 24 BEST PRACTICE & RESEARCH CLINICAL ENDOCRINOLOGY & METABOLISM 325-334 (2010).

³⁹ A Wisniewski & T Mazur, *supra* note 30.

⁴⁰ A Wisniewski & T Mazur, *supra* note 30; IA Hughes et al., *supra* note 2.

⁴¹ IA Hughes et al., *supra* note 2.

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.”⁴² 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.⁴³ 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.*⁴⁴

4. 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 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,” researchers in the United States were enrolling the prenatally treated children in research studies after treatment, in order to determine if it was in fact safe.⁴⁵ 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

⁴² IA Hughes et al., *supra* note 2.

⁴³ K Karkazis, A Kon & A Tamar-Mattis, *supra* note 7.

⁴⁴ Alexander, *supra* note 15.

⁴⁵ A Dreger, EK Feder EK & A Tamar-Mattis, *Prenatal Dexamethasone for Congenital Adrenal Hyperplasia*, 9 J. OF BIOETHICAL INQUIRY 277-294 (2012).

to state, “We find it unacceptable that, globally, fetuses at risk for CAH are still treated prenatally with DEX without follow-up.”⁴⁶

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.⁴⁷ 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.

5. Denial of Needed Healthcare

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**, and of a **newborn infant in Egypt who was refused life-saving treatment at a hospital due partly to discrimination based on his intersex condition.**

How Medical Treatment of People with Intersex Conditions Fits into the Torture and CIDT Framework

Many of the violations visited on people with intersex conditions have already been recognized as torture or CIDT. Various human rights bodies have recognized that coerced sterilization can constitute 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.⁴⁸ **The U.N. Special Rapporteur on Torture and the U.N. Special Rapporteur on Violence against Women have made it clear that FGM constitutes torture⁴⁹ and that, from a human rights perspective, the medicalization of FGM – its performance in clinical surroundings – does not make**

⁴⁶ T Hirvikoski et al., *Prenatal dexamethasone treatment of children at risk for congenital adrenal hyperplasia: The Swedish experience and standpoint*, 97 THE J. OF CLINICAL ENDOCRINOLOGY AND METABOLISM (2012), doi:10.1210/jc.2012- 1222.

⁴⁷ J Yang & D Poppas, *Nerve Sparing Ventral Clitoroplasty: Analysis of Clitoral Sensitivity and Viability*, 178 J. OF UROLOGY 1598-1601 (2007); A Dreger A & EK Feder, *Bad Vibrations*. BIOETHICS FORUM (2010), available at <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4730>.

⁴⁸ U.N. Committee Against Torture, *General Comment No. 2*, CAT/C/GC/2 (2007).

⁴⁹ *Report of the Special Rapporteur on violence against women, its causes and consequences*, U.N. Doc. E/CN.4/2002/83 (2002).

this practice more acceptable.⁵⁰ No exception has been mentioned for cutting girls' genitals for social or cultural reasons when the girl happens to have an intersex condition. The U.N. 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.⁵¹ **The Committee has called upon States to prohibit by law the involuntary sterilisation of children on grounds of disability.**⁵² Again, no exception has been mentioned for children whose medical condition happens to cause atypical sex characteristics.

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") suggest that, at a minimum, CIDT covers "treatment as deliberately causing severe suffering, mental or physical, which in the particular situation is unjustifiable."⁵³ The U.N. 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.*⁵⁴

Under these interpretations, the medical practices described above constitute torture or CIDT in violation of Article 1(1) of the Convention. **These procedures are intentional and performed for discriminatory and non-medical purposes; are performed with state control, custody or consent; can cause severe physical and psychological pain or suffering; and involve children who are powerless to refuse.**

1. 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

⁵⁰ *Report of the Special Rapporteur on Torture on torture and other cruel, inhuman or degrading treatment or punishment*, U.N. Doc. A/HRC/7/3 (2008).

⁵¹ U.N. Committee on the Rights of the Child, *General Comment No. 13: The Right Of The Child To Freedom From All Forms Of Violence* (2011).

⁵² U.N. Committee on the Rights of the Child, *General Comment No. 13: The Right Of The Child To Freedom From All Forms Of Violence* (2011); U.N. Committee on the Rights of the Child, *General comment No. 9,: The rights of children with disabilities* (2007).

⁵³ M Nowak, *What Practices Constitute Torture?*, 28 HUMAN RIGHTS QUARTERLY 821 (2006),(quoting Human Rights Watch, *Torture and Cruel Treatment in Health Settings*).

⁵⁴ *Interim report of the Special Rapporteur on Torture on the question of torture and other cruel, inhuman or degrading treatment or punishment*, U.N. Doc. A/63/175 (2008).

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.⁵⁵ 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.⁵⁶ 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.”⁵⁷

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.⁵⁸

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.⁵⁹ 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.⁶⁰ Enabling heterosexual intercourse is often an important goal,⁶¹ 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.⁶² Very few focus on psychological well-being, patient satisfaction, or sexual pleasure or function.⁶³ The goals and mode of treatment also differ

⁵⁵ U.N. Committee Against Torture, *General Comment No. 2*, CAT/C/GC/2 (2007).

⁵⁶ *Interim report of the Special Rapporteur on Torture on the question of torture and other cruel, inhuman or degrading treatment or punishment*, U.N. Doc. A/63/175 (2008).

⁵⁷ *Interim report of the Special Rapporteur on Torture on the question of torture and other cruel, inhuman or degrading treatment or punishment*, U.N. Doc. A/63/175 (2008).

⁵⁸ IA Hughes et al., *supra* note 2.

⁵⁹ Association of Intersexual People, *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* (2011), http://intersex.shadowreport.org/public/Association_of_Intersexed_People-Shadow_Report_CAT_2011.pdf.

⁶⁰ S Creighton, et al., *supra* note 6.

⁶¹ S Creighton, et al., *supra* note 6.

⁶² L-M Liao et al., *Determinant factors of gender identity: A commentary*, J. OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpurol.2012.09.009>; A Wisniewski & T Mazur, *46, XY DSD with female or ambiguous external genitalia at birth due to Androgen Insensitivity Syndrome, 5-Reductase-2 Deficiency, or 17-Hydroxysteroid Dehydrogenase Deficiency: a review of quality of life outcomes*. INT’L J. OF PEDIATRIC ENDOCRINOLOGY (2009).

⁶³ L-M Liao et al., *Determinant factors of gender identity: A commentary*, J. OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpurol.2012.09.009>; PT Cohen-Kettenis, *Psychosocial And Psychosexual*

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.⁶⁴

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.”⁶⁵ 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.⁶⁶ 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.⁶⁷

Doctors are also aware that there is usually no medical necessity for genital-normalizing surgery, and offer social justifications, believing that these procedures are 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

Aspects Of Disorders Of Sex Development, 24 BEST PRACTICE & RESEARCH CLINICAL ENDOCRINOLOGY & METABOLISM 325-334 (2010).

⁶⁴ A Tamar-Mattis, *Sterilization and minors with intersex conditions in California law*, 3 CAL. L. REV. CIRCUIT 126-135 (2012); K KARKAZIS, *supra* note 5; IA Hughes et al., *supra* note 2.

⁶⁵ P.S. Furtado et al., *Gender dysphoria associated with disorders of sex development*, NAT. REV. UROL. (2012); doi:10.1038/nrurol.2012.182.

⁶⁶ *Id.*

⁶⁷ IA Hughes et al., *supra* note 2.

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.⁶⁸ 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.*⁶⁹

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.”**⁷⁰

2. State Control, Custody, or Consent

In general, the state-action component of the medical treatment of children with intersex conditions does not differ from that of other medical treatments being explored by the SRT, so we will not address this issue in great detail here. However, there are a few salient points worth raising.

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.⁷¹ The Special Rapporteur on Torture has emphasized that the obligation to prevent torture extends “to doctors, health professionals and social workers,

⁶⁸ *Id.*

⁶⁹ Swiss National Advisory Commission on Biomedical Ethics, *On the management of differences of sex development: Ethical issues relating to "intersexuality,"* Opinion No. 20/2012 (2012).

⁷⁰ A Tamar-Mattis, *Exceptions To The Rule: Curing The Law's Failure To Protect Intersex Children*, 21 BERKELEY J. OF GENDER, L. & JUST. 59 (2006); A Tamar-Mattis, *Sterilization and minors with intersex conditions in California law*, 3 CAL. L. REV. CIRCUIT 126-135 (2012);

⁷¹ U.N. Committee Against Torture, *General Comment No. 2*, CAT/C/GC/2 (2007).

including those working in private hospitals [or] other institutions.”⁷² 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 similar in its particulars and in its social justification to the genital surgery endured by children with intersex conditions, the Rapporteur 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.⁷³ 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.⁷⁴

3. Infliction of Severe Pain or Suffering

The U.N. 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.⁷⁵ 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, or of some forms of FGM.⁷⁶

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

⁷² *Interim report of the Special Rapporteur on Torture on the question of torture and other cruel, inhuman or degrading treatment or punishment*, U.N. Doc. A/63/175 (2008).

⁷³ *Interim report of the Special Rapporteur on Torture on the question of torture and other cruel, inhuman or degrading treatment or punishment*, U.N. Doc. A/63/175 (2008).

⁷⁴ A Tamar-Mattis, *Exceptions To The Rule: Curing The Law's Failure To Protect Intersex Children*, 21 BERKELEY J. OF GENDER, L. & JUST. 59 (2006).

⁷⁵ Report of the Special Rapporteur on Torture, U.N. Doc. E/CN. 4/1996/35 (1996).

⁷⁶ Alexander, *supra* note 15; N Ehrenreich, *Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices,"* 40 HARV. C.R. – C.L. L. REV. 71 (2005).

fails and cannot be undone.⁷⁷ Many intersex people report a level of trauma and fear of doctors that renders them unable to access even ordinary medical care.⁷⁸ 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.

4. 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.**⁷⁹ Soon after the birth of a child with an atypical body, they are 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.⁸⁰ We have received numerous reports of parents who question the need for early genital surgery and are **pressured by doctors with scenarios of suicide, cancer, “gender confusion,” and ostracization, or even threatened with loss of medical care or reports to child abuse authorities.**

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 to meet the definition of cruel, inhuman or degrading treatment as prohibited by Article 16.

We welcome the recognition of such mistreatment in the Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment,

⁷⁷ S Creighton, et al., *supra* note 6; San Francisco Human Rights Commission, *A Human Rights Investigation Into The Medical “Normalization” Of Intersex People* (2005), available at http://sfhrc.org/site/uploadedfiles/sfhumanrights/Committee_Meetings/Lesbian_Gay_Bisexual_Transgender/HRC%20Intersex%20Report.pdf; P Lee, et al., *Review of recent outcome data of disorders of sex development (DSD): Emphasis on surgical and sexual outcomes*, J. OF PEDIATRIC UROLOGY (2012), <http://dx.doi.org/10.1016/j.jpurol.2012.10.017>.

⁷⁸ San Francisco Human Rights Commission, *A Human Rights Investigation Into The Medical “Normalization” Of Intersex People* (2005), available at http://sfhrc.org/site/uploadedfiles/sfhumanrights/Committee_Meetings/Lesbian_Gay_Bisexual_Transgender/HRC%20Intersex%20Report.pdf; K KARKAZIS, *supra* note 5.

⁷⁹ K KARKAZIS, *supra* note 5.

⁸⁰ K KARKAZIS, *supra* note 5; K Karkazis, A Kon & A Tamar-Mattis, *supra* note 7.

which states:

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.

And that:

These procedures [genital-normalizing surgeries] are rarely medically necessary, can cause scarring, loss of sexual sensation, pain, incontinence and lifelong depression and have also been criticized as being unscientific, potentially harmful and contributing to stigma.

We especially welcome the Special Rapporteur’s call for an end to such treatment:

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, medical display, “reparative therapies” or “conversion therapies”, 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.

For the SRT to recognize that the childhood genital-normalizing surgery, involuntary sterilization, unethical experimentation, and medical display experienced by intersex people rises to the level of torture and CIDT represents an **enormous step forward in ending these abuses**. Currently these treatments are widely recognized as “controversial” and are promulgated by a small cadre of specialist providers. Non-surgeons on treatment teams may feel uncomfortable challenging surgical decisions.⁸¹ Recognizing these procedures as torture and CIDT gives support to the many medical providers who already question these treatments.

Our recommendations for states working to prevent torture and ill-treatment of intersex people in health care settings are:

1. **Cease all involuntary 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.
2. **Cease all involuntary cosmetic surgery on children’s genitals**, both in public and in private settings.
3. Where genital surgery on a minor is deemed medically necessary, **require independent oversight by a court or other body** competent to weigh the evidence impartially and to independently consider the child’s best interest.

⁸¹ S Creighton, et al., *supra* note 6.

4. **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; and on the existence of support groups.
5. **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.
6. Include **specific vocational training** of medical professionals on intersex conditions in all medical and psychological disciplines.
7. **Enforce existing laws relating to involuntary sterilization and female genital mutilation** where children with intersex conditions are involved.
8. **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.
9. **Ensure that research involving intersex people complies with all legal requirements for protection of human research subjects**, and that ethical oversight of such research is informed by members of the intersex community.
10. **Ensure that medical professionals are educated about the harm caused by medical display and photography** and that they are able to distinguish genital exams necessary for treatment from those that do not benefit the patient.
11. Provide **access to needed medical treatment without discrimination**, including hormone substitution corresponding with the individual's gender identity.
12. 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 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:
 - 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.