

Recommendations from interACT: Advocates for Intersex Youth regarding the List of Issues for the United States for the 59th Session of the Committee Against Torture

June 2016

Despite continuous international condemnation *and their own explicit recognition that non-consensual genital surgeries on intersex children have been classified as torture by the United Nations*, physicians in the United States continue to perform intersex genital mutilation. Thus, interACT (formerly known as Advocates for Informed Choice) implores the Committee Against Torture to include the treatment of intersex children in its List of Issues for the United States in the 59th Session.

1. interACT, formerly known as Advocates for Informed Choice, is an independent human rights NGO based in the United States. It is the first and only organization in the country exclusively dedicated to advocacy on behalf of children born with intersex traits. The term “intersex” refers to variations in a person’s sexual or reproductive anatomy such that their body does not fit typical definitions of male or female, and includes many different medical conditions including androgen insensitivity syndrome, virilizing congenital adrenal hyperplasia (CAH), Klinefelter’s syndrome, Turner syndrome, hypospadias, bladder exstrophy, and others. Common estimates of the frequency of intersex births are between one in 1,000 and one in 2,000.¹
2. Beginning in infancy and continuing throughout childhood, children with intersex traits in the United States have been, and continue to be, subjected to intersex genital mutilation (IGM). These children often experience irreversible sex assignment and sterilization, medical display and photography of the genitals, and medical experimentation. People with intersex traits 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 constitute torture as recognized by multiple international human rights bodies.
3. In 2013, the Special Rapporteur on Torture “call[ed] 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 the states to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to

¹ Blackless M, et al. 2000. How sexually dimorphic are we? Review and synthesis. American Journal of Human Biology 2000, 12:151-166.

- marginalized groups.”² The Special Rapporteur renewed this call in his 2016 report on gender perspectives on torture.³ In addition, the High Commissioner for Human Rights acknowledged that the rights infringed by the genital-“normalizing” surgeries carried out on intersex children include “their rights to physical integrity, to be free from torture and ill treatment, and to live free from harmful practices.”⁴
4. Following the actions of the SRT, in 2014 the Society for Pediatric Urology of the United States, the professional organization of physicians who perform IGM in this country, published a paper concerning their “standpoint on the surgical management” of intersex traits. They recognized that the practice has been classified as torture but nevertheless failed to call for a ban on such surgeries, instead stating that more information must be gathered and that surgery could be justified “to restore more normal visible anatomy, and avoid ambiguity which is often the parents’ wish.”⁵ However, as we noted in our response, this cannot be an ethical justification for such surgery, and the paper “significantly understate[d] reported catastrophic outcomes including complete loss of sexual sensation, psychological trauma and PTSD, sterilization, and irreversible surgical restructuring of genitals not appropriate to the eventual gender identity.”⁶
 5. Thereafter, in 2015, the World Health Organization, UNICEF, OHCHR, UN Women, UNAIDS, UNDP and UNFPA explained, intersex children “are often subjected to cosmetic and other non-medically indicated surgeries performed on their reproductive organs, without their informed consent or that of their parents, and without taking into consideration the views of the children involved [...] As a result, such children are being subjected to irreversible interventions that have lifelong consequence for their physical and mental health.”⁷ The statement called for accountability, participation, and access to remedies for intersex people.
 6. Yet the practice continues. Just this year, in 2016, a group of prominent physicians published a statement on the treatment of intersex children, “Global Disorders of Sex Development Update since 2006,” and again failed to call for an end to these surgeries despite their recognition of “a number of agencies condemning or calling for a complete moratorium on elective genital surgery or

² Report of the Special Rapporteur on Torture, Juan E. Mendez, UN Doc. A/HRC/22/53 (2013), available at http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

³ Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN Doc A/HRC/32/33 (April 4 2016).

⁴ United Nations Office of the High Commissioner for Human Rights, Free & Equal Fact Sheet: Intersex (2015).

⁵ Mouriquand P., Caldamone A., Malone P., Frank J.D., Hoebeke P. *The ESPU/SPU Standpoint on the Surgical Management of Disorders of Sex Development (DSD)*, 10 JOURNAL OF PEDIATRIC UROLOGY 8 (2014).

⁶ Anne Tamar-Mattis, *Patient Advocate Responds to DSD Surgery Debate*, 10 JOURNAL OF PEDIATRIC UROLOGY 788 (2014).

⁷ WORLD HEALTH ORGANIZATION, *Eliminating forced, coercive or otherwise involuntary sterilization: An interagency statement* (OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO) (2014), available at: http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325_eng.pdf?ua=1.

- gonadectomy without the individual's informed consent" and that "many guidelines deem children's participation and input indispensable to decisions, especially those that will have a life-long deeply personal impact on their lives, with heightened awareness that young children, in particular, may not be able to vocalize adverse reactions to many interventions."⁸ Though the physicians are aware of the human rights violations they perform, the paper instructed them merely to "be aware that the trend in recent years has been for legal and human rights bodies to increasingly emphasize preserving patient autonomy."⁹
7. Many other published papers have recognized the potential for harm against this population, yet intersex children continue to experience genital mutilation in the United States. Physicians argue there must be additional medical research prior to a change in practice, yet unbiased research including the input of the intersex community is nonexistent. This year the Journal of Pediatric Urology published an article proffering to address the aims of genital surgery yet failed to even mention the lack of informed consent when these procedures are performed in infancy, instead avoiding the issue altogether and asserting that while "surgery has been restrictively considered by some to be 'cosmetic surgery,' the cosmetic aspect of genitalia and the related stigma risk are also important issues for many patients."¹⁰ Yet, as noted by a Swiss National Advisory Commission on Biomedical Ethics, "[a]n 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 ... 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"¹¹
 8. Recently, doctors at a major United States conference presented information from one registry in the United States (that is currently unavailable to access from patient groups) confirming the frequency of these surgeries as performed on infants. Regarding *initial* surgical intervention for children with Congenital Adrenal Hyperplasia (CAH), one of the more common intersex conditions, they noted "544 patients underwent feminizing genitoplasty between 2004-2014, median age at initial surgery: 9.9 months."¹² If other conditions and surgeries

⁸ Lee PA, Nordenström A, Houk CP, *Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care*, Hormone Research in Pediatrics 158-180 (2016). Available at: <http://www.karger.com/Article/FullText/442975>.

⁹ *Id.*

¹⁰ Mouriquand PD1, Gorduzza DB2, Gay CL, *Surgery in disorders of Sex Development (DSD) with a gender issue: If (why), when, and how?* Journal of Pediatric Urology (2016). Available at: [http://www.jpurology.com/article/S1477-5131\(16\)30012-2/abstract](http://www.jpurology.com/article/S1477-5131(16)30012-2/abstract)

¹¹ Swiss National Advisory Commission on Biomedical Ethics. On the management of differences of sex development: Ethical issues relating to "intersexuality." Opinion No. 20/2012.

¹² The Society for Pediatric Urology Annual Meeting, *Cost analysis and clinical outcomes of feminizing genitoplasty on congenital adrenal hyperplasia using a large scale administrative database* (May 6, 2016). Abstract available at: <http://spuonline.org/abstracts/2016/16.cgi>.

- were considered, such as hypospadias repair, gonadectomy, or follow-up surgeries, that number would increase significantly. This conference included discussions of how to ensure these surgeries continue to be cost-effective/profitable for health care institutions. Our organization receives continual inquiries from families explaining that surgery is or has been pressed upon them in respected hospitals in major cities across the United States.
9. The continued treatment of intersex individuals in the United States clearly meets the CAT's standards for torture: that the action 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 more must be done—even the recognition of the classification of IGM as torture has failed to improve the treatment of intersex youth in the United States.
 10. Much of the “treatment” performed by physicians in the United States has already been recognized as torture or CIDT, as we have explained in previous publications.¹³ Coerced sterilization can constitute torture and CIDT, and states' obligations to protect persons from such treatment extends into the private sphere, including where such practices are committed by private individuals.¹⁴ In the case of FGM, which encompasses the clitoral reduction surgeries carried out on many female-assigned intersex children,¹⁵ 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.¹⁶ However, we are unaware of any jurisdiction in the U.S. that enforces its own FGM laws in cases where the girl undergoing clitoral cutting has an intersex trait. Further, as we have noted previously, the U.N. Committee on the Rights of the Child has addressed involuntary sterilization of persons with disabilities under the age of 18 as a form of violence, in violation of the child's right to physical integrity, causing life-long effects on physical and mental health.¹⁷ The Committee has called upon States to prohibit by law the involuntary sterilization of children on grounds of disability. Again, no exception has been mentioned for children whose medical condition happens to cause atypical sex characteristics.

¹³ Tamar-Mattis, *Medical Treatment of People with Intersex Conditions as Torture and Cruel, Unhuman, or Degrading Treatment or Punishment* in *Torture in Healthcare Settings: reflections on the Special rapporteur on Torture's 2013 Thematic report*.

¹⁴ UN Committee Against Torture, General Comment No. 2 (2007), CAT/C/GC/2.

¹⁵ Fraser S. *Constructing the Female Body: Using Female Genital Mutilation Law to Address Genital-Normalizing Surgery on Intersex Children in the United States*, INTERNATIONAL JOURNAL OF HUMAN RIGHTS IN HEALTHCARE (2016) 9:1, pp. 62-72, available at <http://dx.doi.org/10.1108/IJHRH-05-2015-0014>

¹⁶ Fraser S. *Constructing the Female Body: Using Female Genital Mutilation Law to Address Genital-Normalizing Surgery on Intersex Children in the United States*, INTERNATIONAL JOURNAL OF HUMAN RIGHTS IN HEALTHCARE (2016) 9:1, pp. 62-72, available at <http://dx.doi.org/10.1108/IJHRH-05-2015-0014>

¹⁷ 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).

11. Despite international condemnation from bodies including the World Health Organization, Amnesty International, and multiple committees of the United Nations and the explicit classification of intersex surgery as torture under several frameworks of human rights abuse, in addition to United States physicians' own awareness of their actions, the surgeries inflicted on intersex individuals in the United States continue in flagrant violation of, most notably, the Convention Against Torture and the mandate of the Special Rapporteur on Torture (SRT 2013).
12. Thus, interACT files this submission to inform the List of Issues for the United States for the Committee against Torture's 59th Session, to occur from November 7 to December 7, 2016. We respectfully request that the Committee consider the following inquiries:
 - **Please provide information on what steps, if any, are being taken by federal and state government bodies to end non-consensual genital surgeries on intersex individuals;**
 - **Please provide information on what steps, if any, are being taken by federal and state government bodies to ensure full and free informed consent is provided in all cases where surgical intervention on an intersex individual is considered;**
 - **Please provide information on what steps, if any, are being taken to provide for full legal review of non-consensual genital surgeries, including FGM and sterilization on intersex individuals;**
 - **Please provide information on what steps, if any, are being taken to address the need for data collection and independent monitoring of births of intersex children and their medical treatment;**
 - **Please provide information on what steps, if any, are being taken to address the need for disinterested research on long-term patient satisfaction of surgical and other procedures on intersex children, in consultation with intersex individuals and their organizations.**

Sincerely,



Anne Tamar-Mattis
Legal Director