**Non-consensual genital surgeries on intersex children constitute torture and cruel, inhuman, and degrading treatment in violation of the ICCPR**

1. **Reporting Organization**

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.

1. **Issue Summary**

The term “intersex” refers to variations in a person’s sex traits, including chromosomes, genitals, hormone production, and internal organs, such that their body does not fit typical definitions of male or female. It is an umbrella term that includes many different medical diagnoses, as well as variations in sex characteristics without a diagnosable etiology. Conservative estimates of the frequency of intersex births are between one in 1,000 and one in 2,000,[[1]](#endnote-1) while higher estimates reach up to 1.7 percent.[[2]](#endnote-2)

Beginning in infancy and continuing throughout childhood, children with intersex traits in the U.S. have been, and continue to be, subjected to intersex genital mutilation (IGM) and other unnecessary medical interventions to change their sex traits without their consent. These children often experience irreversible genital surgery, sex assignment, and sterilization; medical display and photography of the genitals; and unethical medical experimentation. People with intersex traits may also be discriminatorily denied necessary medical treatment. Intersex individuals suffer life-long physical and emotional injury as a result of such experiences. These human rights violations often involve tremendous physical and psychological pain and constitute torture as recognized by multiple international human rights bodies.

1. **Concluding Observations and ICCPR Legal Framework**

**Relevant ICCPR Articles**: **Article 3**, Equal protection of civil and political rights; **Article 7**, Prohibition against torture, cruel, inhuman or degrading treatment or punishment; **Article 9**, Liberty and security of the person; **Article 14**, Equality before the courts; **Article 17**, Privacy; **Article 24**, Non-discrimination on the basis of sex and birth; **Article 26**, All persons are equal before the law and entitled to equal protection of the law without discrimination.

In 2018, the Committee expressed concern “that the performance of surgical procedures on intersex children, causing physical and mental suffering, is still not strictly regulated.”[[3]](#endnote-3) The Committee recommended that the State party take steps to “ensure that no child undergoes unnecessary surgery intended to assign sex.”[[4]](#endnote-4) The Committee further recommended that inquiries be launched when intersex persons have not given consent for surgery or treatment, and suggested the State should provide psychological resources and reparation, including compensation for such victims.[[5]](#endnote-5) The Committee explicitly referenced arts. 3, 7, 24, and 26 of the ICCPR.[[6]](#endnote-6)

In 2017, the Committee noted that Australia’s practice of “irreversible and invasive medical interventions for purposes of gender assignment” on children born with intersex variations is in violation of articles 3, 7, 9, 17, 24, and 26 of the ICCPR.[[7]](#endnote-7) The Committee recommended that these procedures not be performed without the informed consent of the individual unless it is medically necessary.[[8]](#endnote-8)

1. **Current U.S. Government Policy or Practice: The practice of intersex genital mutilation on children with intersex traits constitutes cruel, inhuman, or degrading treatment (CIDT) and torture**

Much of the “treatment” performed on intersex individuals by physicians in the U.S. has already been recognized as torture or CIDT.[[9]](#endnote-9) Procedures where intersex children’s gonads or other organs are removed without their consent can be sterilizing. 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.[[10]](#endnote-10) 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.[[11]](#endnote-11) The Committee has called upon States to prohibit by law the involuntary sterilization of children on grounds of disability. No exception has been mentioned for children whose medical condition happens to cause atypical sex characteristics.

In addition to sterilization, many serious and documented risks accompany non-consensual medical interventions on intersex children. Removal of hormone-producing gonads often requires that the individual be placed onto lifelong hormone replacement therapy. Genital surgeries risk the irreversible loss of sexual sensation and function, urinary incontinence, and chronic pain.[[12]](#endnote-12) Any procedure that alters a child’s sex traits to conform to what is typical for the assigned sex enhances the risks of assigning a sex that doesn’t match their gender identity.[[13]](#endnote-13) Depending on the intersex diagnosis, the probability of assigning a sex with which the individual will not identify ranges from 5 up to 60 percent.[[14]](#endnote-14) In the case of female genital mutilation (FGM), which encompasses the clitoral reduction surgeries carried out on many female-assigned intersex children,[[15]](#endnote-15) the United Nations Special Rapporteur on Torture (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]](#endnote-16) However, we are unaware of any jurisdiction in the U.S. that enforces FGM laws in cases where the girl undergoing clitoral cutting has an intersex trait.

Following the actions of the SRT, in 2014 the Societies for Pediatric Urology published a paper concerning their “standpoint on the surgical management” of intersex traits. They recognized that non-consensual and unnecessary interventions on intersex children have 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.”[[17]](#endnote-17) HoHwever, these subjective considerations cannot be ethical justifications for such surgery on unconsenting individuals. Intersex advocates additionally pointed out that the urologists’ 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.”[[18]](#endnote-18)

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 consequences for their physical and mental health.”[[19]](#endnote-19) The statement called for accountability, participation, and access to remedies for intersex people.

In 2016, a group of prominent physicians published a statement on the treatment of intersex children, 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 gonadectomy without the individual’s informed consent”[[20]](#endnote-20) 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.”[[21]](#endnote-21) The paper instructed physicians treating intersex patients merely to “be aware that the trend in recent years has been for legal and human rights bodies to increasingly emphasize preserving patient autonomy.”[[22]](#endnote-22) However, in direct defiance of preserving patient autonomy, medically unnecessary and non-consensual interventions on the sex traits of intersex children continue today.[[23]](#endnote-23)

Many other published papers have recognized the potential for harm, yet intersex children continue to experience genital mutilation in the U.S.[[24]](#endnote-24) Physicians in support of the current paradigm argue there must be additional research prior to a change in practice, yet this excuse has been used for decades while unbiased medical research centering the input of the intersex community remains nonexistent. Conversely, intersex patient advocates point out that “there has never been sufficient research to show either that these surgeries benefit patients or that there is any harm from growing up with atypical genitals.”[[25]](#endnote-25) Proponents of performing unnecessary surgery in childhood often rely on the presumed stigma and psychological distress related to having a body that may be considered atypical as justifications for operating before the individual can give informed consent. The *Journal of Pediatric Urology* published an article 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.”[[26]](#endnote-26) One article cited “maintenance of ambiguous genital anatomy and its unknown psychological ramifications” as a disadvantage of not operating on intersex children’s genitalia.[[27]](#endnote-27) Yet, recent research shows intersex children who are growing up without medically unnecessary surgery are not showing signs of psychological distress or expressing concerns related to their unaltered genitals.[[28]](#endnote-28) This suggests that such “justifications” for surgery are more reflective of doctors’ and parents’ concerns than those of the intersex individual. 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.”[[29]](#endnote-29)

Doctors in the U.S. may also claim that surgeries on intersex children are performed infrequently, or only in cases of medical necessity. Findings from their own publications and presentations contradict this. Doctors at a major U.S. conference presented information from one registry in the U.S. regarding surgery on children with Congenital Adrenal Hyperplasia (CAH), one of the more common intersex conditions. They noted “544 patients underwent feminizing genitoplasty between 2004-2014,” with a median age at initial surgery of just 9.9 months.[[30]](#endnote-30) This conference included discussions of how to ensure these surgeries continue to be cost- effective/profitable for health care institutions. One study on intersex babies documented that 25 of 26 participants had undergone genital surgeries.[[31]](#endnote-31) Our organization receives continual inquiries from families who tell us that surgery is being or has been pressed upon them in respected hospitals in major cities across the U.S.

Recent efforts to create legislation to protect the rights of intersex individuals are promising but tend to fall short in terms of enforcement. In 2018, California’s legislature passed a resolution supporting the autonomy of intersex people and their right to choose whether to have surgery or other interventions on their sex characteristics.[[32]](#endnote-32) This resolution, while a victory for the intersex community in terms of affirmation and awareness, is non-binding and contains no enforcement mechanisms to curtail the practice of non-consensual surgery. Furthermore, laws that are on the books are not being applied to protect intersex individuals. In the first known prosecution under the federal FGM law, a U.S. district judge in Michigan recently ruled that the FGM ban was unconstitutional, resulting in FGM charges being dropped against a doctor accused of performing unnecessary genital cutting on young children.[[33]](#endnote-33) The case will likely be appealed, but it nevertheless raises questions about the nation’s commitment to addressing this practice.

The ongoing treatment of intersex individuals in the U.S. clearly meets the CAT’s standards for torture: that the action be intentional and performed for discriminatory and non-medical purposes; be 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 U.S.

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, the non-consensual surgeries inflicted on intersex individuals in the U.S. continue in flagrant violation of the ICCPR.

1. **Human Rights Committee General Comments**

General comment No. 35 on article 9 notes that “[s]ecurity of person concerns freedom from injury to the body and the mind, or bodily and mental integrity.”[[34]](#endnote-34) General comment No. 36 clarifies that the right to life includes the right “to enjoy a life with dignity.”[[35]](#endnote-35) IGM violates both articles 9 and 6 by inflicting injury to the body and mind as well as interferes with the victim’s right to enjoy a life with dignity.

1. **Other UN Body Recommendations**

In 2013, the SRT “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.[[36]](#endnote-36) The SRT also called upon the states to outlaw forced or coerced sterilization in all circumstances and provide special protection to individuals belonging to marginalized groups."[[37]](#endnote-37) The Special Rapporteur renewed this call in his 2016 report on gender perspectives on torture.[[38]](#endnote-38)

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.”[[39]](#endnote-39)

The Committee on the Rights of the Child (CRC) reiterated the call to end forced surgeries or treatments on intersex adolescents.[[40]](#endnote-40) The Committee made further recommendations that protocols for intersex children should be established to ensure no one is subjected to unnecessary medical treatment and to “guarantee[] the rights of children to bodily integrity, autonomy, and self-determination.”[[41]](#endnote-41)

Finally, various UN and regional bodies signed a call for the end of human rights violations against intersex children and adults, describing the practice of medically unnecessary surgeries as torture.[[42]](#endnote-42)

1. **Recommended Questions**
	1. What steps, if any, are being taken by national and subnational government bodies to end non-consensual genital surgeries on intersex individuals?
	2. What steps, if any, are being taken by national and subnational government bodies to ensure full and free informed consent is provided in all cases where surgical intervention on an intersex individual is considered?
	3. 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?
	4. 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?
	5. 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?

**VIII. Acknowledgements**

interACT extends deep thanks to Alissa Weinberger, Martha F. Davis, and Northeastern Law School’s Program on Human Rights and the Global Economy for their support in the creation of this submission.

1. Blackless M, et al. 2000. *How sexually dimorphic are we? Review and synthesis.* American Journal of Human Biology 2000, 12:151-166. [↑](#endnote-ref-1)
2. United Nations Office of the High Commissioner for Human Rights, Free & Equal,Fact Sheet: Intersex (2015). [↑](#endnote-ref-2)
3. Human Rights Committee, *Concluding observations on the fourth periodic report of Switzerland* 4 (22 August 2017) *available at* <https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CCPR%2fC%2fCHE%2fCO%2f4&Lang=en>. [↑](#endnote-ref-3)
4. *Id*. [↑](#endnote-ref-4)
5. *Id*. [↑](#endnote-ref-5)
6. *Id*. [↑](#endnote-ref-6)
7. Human Rights Committee, *Concluding observations on the sixth periodic report of Australia* 5 (9 November 2017) *available at* https://tbinternet.ohchr.org/Treaties/CCPR/Shared%20Documents/AUS/INT\_CCPR\_COC\_AUS\_29445\_E.pdf. [↑](#endnote-ref-7)
8. *Id*. [↑](#endnote-ref-8)
9. Tamar-Mattis A, *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. [↑](#endnote-ref-9)
10. UN Committee Against Torture, *General Comment No. 2* (2007), CAT/C/GC/2. [↑](#endnote-ref-10)
11. 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). [↑](#endnote-ref-11)
12. *Id*. [↑](#endnote-ref-12)
13. Human Rights Watch and interACT, *“I Want To Be Like Nature Made Me”: Medically Unnecessary Surgeries on Intersex Children in the US* 58 (2017) *available at* https://www.hrw.org/sites/default/files/report\_pdf/lgbtintersex0717\_web\_0.pdf. [↑](#endnote-ref-13)
14. Hughes IA et al., *Consensus Statement on Management of Intersex Disorders*, 91 Archives of Disease in Childhood554(2006); Furtado PS et al., *Gender Dysphoria Associated with Disorders of Sex Development,* Nat. Rev. Urol*.* (9 October 2012), available at doi:10.1038/nrurol.2012.182. [↑](#endnote-ref-14)
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>. [↑](#endnote-ref-15)
16. *Id*. [↑](#endnote-ref-16)
17. 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). [↑](#endnote-ref-17)
18. Anne Tamar-Mattis, *Patient Advocate Responds to DSD Surgery Debate*, 10 JOURNAL OF PEDIATRIC UROLOGY 788 (2014). [↑](#endnote-ref-18)
19. 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>. [↑](#endnote-ref-19)
20. 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>. [↑](#endnote-ref-20)
21. *Id*. [↑](#endnote-ref-21)
22. *Id*. [↑](#endnote-ref-22)
23. Diamond, D., Swartz, J., Tishelman, A., et al., *Management of pediatric patients with DSD and ambiguous genitalia: Balancing the child’s moral claims to self-determination with parental values and preferences*, Journal of Pediatric Urology (2018) available at <file:///Users/alissaweinberger/Downloads/1-s2.0-S1477513118302225-main.pdf>. [↑](#endnote-ref-23)
24. Human Rights Watch and interACT, *“I Want To Be Like Nature Made Me”: Medically Unnecessary Surgeries on Intersex Children in the US* 8-9 (2017) *available at* <https://www.hrw.org/sites/default/files/report_pdf/lgbtintersex0717_web_0.pdf>. [↑](#endnote-ref-24)
25. *Id*. at 8. [↑](#endnote-ref-25)
26. Mouriquand PD, Gorduza DB, 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.jpurol.com/article/S1477-5131(16)30012-2/abstract](http://www.jpurol.com/article/S1477-5131%2816%2930012-2/abstract). [↑](#endnote-ref-26)
27. Diamond, D., Swartz, J., Tishelman, A., et al., *Management of pediatric patients with DSD and ambiguous genitalia: Balancing the child’s moral claims to self-determination with parental values and preferences*, Journal of Pediatric Urology (2018) available at <file:///Users/alissaweinberger/Downloads/1-s2.0-S1477513118302225-main.pdf>. [↑](#endnote-ref-27)
28. Bougneres P, Bouvattier C, Cartigny M, Michala L. Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: a feasibility study. International Journal of Pediatric Endocrinology. 2017;2017(3). doi: 10.1186/s13633-016-0040-8; Callens N, van der Zwan YG, Drop SLS, et al. Do surgical interventions influence psychosexual and cosmetic outcomes in women with disorders of sex development? ISRN Endocrinology. 2012:1-8. doi: 10.5402/2012/276742. [↑](#endnote-ref-28)
29. Swiss National Advisory Commission on Biomedical Ethics. *On the management of differences of sex development: Ethical issues relating to "intersexuality."* Opinion No. 20/2012. [↑](#endnote-ref-29)
30. 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>. [↑](#endnote-ref-30)
31. Ellens, R et al., *Psychological Adjustment in Parents of Children Born with Atypical Genitalia One Year After Their Child Undergoes Genitoplasty*, The Journal of Urology (11 May 2017). [↑](#endnote-ref-31)
32. California Legislative Information, Senate Concurrent *Resolution No. 110,* *Sex characteristics* (11 September 2018) *available at* <https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201720180SCR110>. [↑](#endnote-ref-32)
33. McVeigh, Karen, *‘US is moving backwards’: female genital mutilation ruling a blow to girls at risk*, The Guardian (22 Nov 2018) available at <https://www.theguardian.com/society/2018/nov/22/us-is-moving-backwards-female-genital-mutilation-ruling-a-blow-to-girls-at-risk>. [↑](#endnote-ref-33)
34. United Nations Human Rights Committee, *General comment No. 35, Article 9 (Liberty and security of person)* 1 (16 December 2014) *available at* <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsrdB0H1l5979OVGGB%2bWPAXjdnG1mwFFfPYGIlNfb%2f6T%2fqwtc77%2fKU9JkoeDcTWWPIpCoePGBcMsRmFtoMu58pgnmzjyiyRGkPQekcPKtaaTG>. [↑](#endnote-ref-34)
35. United Nations Human Rights Committee, *General comment No. 36 (2018) on article 6 of the International Covenant on Civil and Political Rights, on the right to life* 1 (30 October 2018) *available at* <https://tbinternet.ohchr.org/Treaties/CCPR/Shared%20Documents/1_Global/CCPR_C_GC_36_8785_E.pdf>. [↑](#endnote-ref-35)
36. 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>. [↑](#endnote-ref-36)
37. *Id*. [↑](#endnote-ref-37)
38. *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). [↑](#endnote-ref-38)
39. United Nations Office of the High Commissioner for Human Rights, *Free & Equal Fact Sheet: Intersex* (2015). [↑](#endnote-ref-39)
40. United Nations Convention on the Rights of the Child, *General comment No. 20 (2016) on the implementation of the rights of the child during adolescence*, 10 (6 December 2016), *available at* <https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRC/C/GC/20&Lang=en>. [↑](#endnote-ref-40)
41. United Nations Committee on the Rights of the Child, *Concluding observations on the fifth periodic report of New Zealand*, 8 (30 September 2016) *available at* <https://tbinternet.ohchr.org/Treaties/CRC/Shared%20Documents/NZL/INT_CRC_COC_NZL_25459_E.pdf>. [↑](#endnote-ref-41)
42. United Nations Office of the High Commissioner for Human Rights, *Intersex Awareness Day: End violence and harmful medical practices on intersex children and adults, UN and regional experts urge* (26 October 2016), *available at* <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=20739&%3BLangID=E>. [↑](#endnote-ref-42)