

Stigma and medical abuse against intersex children contributes to mistreatment and violence against women in reproductive healthcare

I. Reporting Organization

interACT: Advocates for Intersex Youth, formerly known as Advocates for Informed Choice, is an independent human rights NGO based in the United States. It is the oldest and largest organization in the country exclusively dedicated to advocacy on behalf of children born with intersex traits. As part of our advocacy, we also work with parents of intersex children to celebrate and raise awareness of intersex traits as healthy, natural variation, and to resist the medical violence that threatens these children and their families.

II. 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,ⁱ while higher estimates reach up to 1.7 percent.ⁱⁱ

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. Many serious and documented risks accompany non-consensual medical interventions on intersex children. Removal of gonads can be sterilizing and 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.ⁱⁱⁱ 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.^{iv} 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.^v People with intersex traits may also experience unethical medical experimentation, traumatizing medical display and photography of the genitals, and even 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.

The impact of these harmful interventions and the resulting trauma on children invariably affect their parents as well. Parents of intersex children are often misled and pressured by doctors to elect high-risk, unnecessary surgery – a decision that must rest with the intersex individual personally – often in the first six months of their child’s life, without adequate explanations, support, or time to bond with their child.^{vi} interACT regularly hears from parents who express that they experienced confusion, shame, and coercion in the aftermath of giving birth to their intersex child, as doctors pathologized their newborn children with pejorative, medicalizing terms such as “disorder,” “deformity,” or “birth defect.” Surgeons in particular may emphasize their subjective observations about how “abnormal” the child’s genitalia appear,^{vii} and offer unfounded speculations about the social and psychological difficulties that will lie ahead for their children simply due to the way they were born. Parents report that doctors repeatedly press attempts to schedule genital surgery without explaining that it is not medically necessary and without offering the alternative option of delaying surgery until the child can give their own informed consent.^{viii} This leaves parents feeling confused, afraid, and coerced at a time when they are the most vulnerable.

III. Violence Against Intersex Women and Girls

As discussed above, intersex children are frequently subjected to medically unnecessary procedures to “normalize” their sex traits long before they can understand these procedures, let alone give informed consent. Some of these children are girls, and some others who do not ultimately identify as girls are nonetheless assigned female by doctors and accordingly subjected to procedures to “feminize” their bodies. Among the most common of these procedures occurring in infancy and early childhood are clitoral reductions – cosmetic surgeries to reduce the size of the clitoris with no medical purpose.^{ix} Other procedures, such as labiaplasty and vaginoplasty, are also performed on some children, either at the same time or separately from the clitoral reduction. As noted above, these procedures all carry enormous risks of damaging sexual sensation and function, scarring, chronic pain, incontinence, and PTSD, as well as the possibility that surgery will be undertaken to enforce a gender assignment the individual later rejects. Many of these procedures squarely fit the definition of Female Genital Mutilation (FGM) under U.S. federal law and many states’ laws, seeing as they are performed on enumerated genital structures for cosmetic or social reasons rather than for reasons of medical necessity.^x

In addition, some of the procedures performed on intersex children and adolescents are sterilizing. Removal of testes or ovaries (known as gonadectomy), or other structures such as a uterus, can end possible avenues of fertility that would have been available to an individual (either with current technology or technology that may be developed in the future). For example, children with Androgen Insensitivity Syndrome – who have XY chromosomes but convert their naturally produced androgens into estrogen, developing a female-typical phenotype as a result – frequently face the unnecessary removal of their internal testes because doctors perceive them as

incongruous with their visible sex characteristics.^{xi} This both ends natural hormone production (requiring that the child be forced onto lifelong hormone replacement therapy as a result) and removes the possibility that the individual could one day use their own sperm to conceive a child. Despite that involuntary sterilization is recognized as unconstitutional in the U.S., these gonadectomies persist at hospitals all around the country. In addition to the physical consequences with respect to hormone disruption and sterilization, one study found that intersex patients who had undergone gonadectomy suffered an increased risk of suicidality.^{xii}

IV. Violence Against Parents of Intersex Children During Reproductive Care, Birth, and Post-Birth Periods

The stigma against intersex traits and the severe physical and psychological consequences of unnecessary surgery for intersex children also cause fear, confusion, and distress for the parents of these children, who usually face a lack of information and support in medical settings both before and after the child's birth. Some research shows that parental distress affects mothers more severely than fathers. One multicenter study of parental distress before and after their child underwent genital surgery found heightened levels of certain measures of distress for mothers at both points compared to fathers.^{†xiii} In addition, mothers may suffer stigmatization and a lack of support during pregnancy if they are (or might be) carrying an intersex fetus. When indications of intersex traits show up on ultrasound or via other testing, medical professionals may recommend risky drug regimens prenatally solely to try to reduce genital "atypicality" by the time of birth, or even encourage abortion of an otherwise wanted fetus.^{xiv} Immediately after giving birth, mothers may be subjected to invasive and abusive questions, with one family reporting that their doctor – hours after delivery – asked whether the mother and father were related to one another as a possible explanation for their child having been born intersex.^{xv} Intersex infants may also be improperly placed in the NICU when no emergent health concern exists that would require special care or monitoring, causing tremendous unnecessary distress to the new parents.^{xvi}

Once the subject surgery is broached, the parents' experience of pressure and medical coercion begins. While intersex advocates maintain that the only truly informed consent to a procedure that alters an intersex individual's sex traits absent a medical emergency is consent *from the intersex individual themselves*, even the purported consent secured from the parent(s) is far from fully informed. Parents are only rarely told about the above-described risks to their child's future physical, sexual, reproductive, and psychological health, and also rarely informed that delaying unnecessary surgery until their child can assess whether they would like any procedures is even an option. Instead, many parents report being rushed through a surgical

[†] Distress, in this context, is very likely influenced by doctors' presentation of their child's intersex traits, and the misinformation and pressure around unnecessary surgery – less due to the child's intersex traits themselves, as other studies show that receiving affirming psychosocial and peer support can help parents adjust to raising an intersex child with significantly better psychological outcomes.

decision-making process by doctors who presented immediate genital-“normalizing” procedures as the only sound option, even having their fitness as parents questioned if they expressed hesitation or resistance to this approach.^{xvii} In what is essentially the opposite of informed consent, parents may have their questions deflected or dismissed, and encounter difficulty and hostility when standing up to surgical pressure.

Parents of intersex children often face immense pressure to allow harm to come to their children in medical settings where they are supposed to be safest. If damaging surgeries are carried out, the child’s experience of growing up with the resulting physical and psychological trauma can seriously impact parents’ well-being as well. Parents report experiencing high levels of decisional regret after agreeing, without adequate information or support, to surgeries they later realize have harmed their children.^{xviii} Even parents who successfully refuse these unnecessary surgeries on behalf of their children may continue to experience pressure to have them performed as their children grow up. interACT even received one recent report that an intersex child was removed from their parents and taken into state custody because the parents refused to consent to an unnecessary surgery that the child also did not want. State-sanctioned separation of children from their parents has been described as an act of violence against children and families in many contexts.

V. Current U.S. Government Policy or Practice: Despite Widespread Condemnation, Official Action is Lacking

Much of the “treatment” performed on intersex individuals by physicians in the U.S. has already been recognized as torture or CIDT.^{xix} 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.^{xx} Further, 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.^{xxi} 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 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.^{xxii} In the case of female genital mutilation (FGM), which encompasses the clitoral reduction surgeries carried out on many female-assigned intersex children,^{xxiii} 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.^{xxiv} 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.^{xxv} The Special Rapporteur renewed this call in his 2016 report on gender perspectives on torture.^{xxvi}

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.”^{xxvii} The Committee on the Rights of the Child (CRC) reiterated the call to end forced surgeries or treatments on intersex adolescents.^{xxviii} 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.”^{xxix} 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.^{xxx}

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.”^{xxxi} However, 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.”^{xxxii}

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.”^{xxxiii} 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”^{xxxiv} 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.”^{xxxv} 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.”^{xxxvi} However, in direct defiance of preserving patient autonomy, medically unnecessary and non-consensual interventions on the sex traits of intersex children continue today.^{xxxvii}

Many other published papers have recognized the potential for harm, yet intersex children continue to experience genital mutilation in the U.S.^{xxxviii} 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.”^{xxxix} 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.”^{xl} One article cited “maintenance of ambiguous genital anatomy and its unknown psychological ramifications” as a disadvantage of not operating on intersex children’s genitalia.^{xli} 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.^{xlii} 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.”^{xliii}

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.^{xliv} 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.^{xlv} interACT is also in possession of data from two U.S. states on rates of state-funded surgeries on intersex children that refutes the claim that these procedures are decreasing in frequency, and we receive 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.^{xlvi} 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. Subsequently, Cook County in Illinois also passed a resolution that named and condemned the harms of unnecessary surgeries performed on intersex children without their consent,^{xlvii} but similarly offers no direct pathway to enforcement. 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.^{xlviii}

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. To date, no U.S. hospital has adopted an explicit policy against harmful, unnecessary surgeries on intersex infants and children. interACT is, however, aware of one case in which a hospital declined to unnecessarily remove an intersex child’s testes, citing Washington state sterilization law as prohibiting the procedure absent court approval.^{xlix}

VI. Conclusion

Many forms of violence against intersex women and girls, as well as mothers and other parents of intersex children, exist throughout reproductive healthcare, childbirth, and the post-birth period when unnecessary surgery commonly begins to be forcefully recommended to the child’s parents. Within the U.S., government responses to these abuses are almost non-existent, with the exception of two non-binding state and local resolutions recommending that these practices end; attempts to pass binding legislation or encourage investigation by state- and national-level authorities have not ultimately resulted in any decisive action. In the absence of an enforceable government mandate, no health facility has independently adopted a policy affirmatively preventing these kinds of harms from occurring. Work by NGOs such as interACT continues with a goal of holding perpetrators accountable.

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