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Medically Unnecessary Operations Risk Lifelong Suffering

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(Chicago, July 25, 2017) Doctors in the United States continue to perform medically unnecessary surgeries that can inflict permanent harm on intersex children, Human Rights Watch and interACT said in a report released today. Despite decades of controversy over the procedures, doctors operate on childrens gonads, internal sex organs, and genitals when they are too young to participate in the decision, even though the surgeries could be safely deferred.

The 160-page report, [I Want to Be Like Nature Made Me: Medically Unnecessary Surgeries on Intersex Children in the US](#), examines the physical and psychological damage caused by medically unnecessary surgery on intersex people, who are born with chromosomes, gonads, sex organs, or genitalia that differ from those seen as socially typical for boys and girls. The report examines the controversy over the operations inside the medical community, and the pressure on parents to opt for surgery.

Once called hermaphrodites (a term now considered pejorative and outdated), intersex people are not rare, but they are widely misunderstood. Based on a medical theory popularized in the 1960s, doctors perform surgery on intersex children often in infancy with the stated aim of making it easier for them to grow up normal. The results are often catastrophic, the supposed benefits are largely unproven, and there are rarely urgent health considerations requiring immediate, irreversible intervention.

The devastation caused by medically unnecessary surgery on intersex infants is both physical and psychological, said Kimberly Zieselman, an intersex woman and executive director of [interACT](#). Despite decades of patient advocates putting the medical community on notice about the harm from these procedures, many doctors continue to present these surgeries to parents as good options.

As many as 1.7 percent of babies are different from what is typically called a boy or a girl. The chromosomes, gonads, internal, or external sex organs of these children differ from social expectations. Some intersex traits such as atypical external genitalia are apparent at birth. Others such as gonads or chromosomes that do not match the expectations of the assigned sex may manifest later in life, in some cases around puberty. A child can be raised as either sex without surgery. On the other hand, genital or gonadal surgeries on intersex children too young to declare their gender identity carry the risk of surgically assigning the wrong sex.

Surgery to remove gonads can amount to sterilization without the patients consent, and then require lifelong hormone replacement therapy. Operations to alter the size or appearance of childrens genitals risk incontinence, scarring, lack of sensation, and psychological trauma. The procedures are irreversible, nerves that are severed cannot regrow, and scar tissue can limit options for future surgery.

Medical protocols have evolved in particular with an increasingly common use of multi-disciplinary teams that work on cases of Differences of Sex Development. Most medical practitioners now acknowledge that parents may prefer to leave their child's body intact. A doctor who works on such a team told Human Rights Watch: We're listening to the adult patients who are telling us that they feel they were mistreated and mutilated and that's a very powerful thing.

Medically Unnecessary Surgeries on Intersex Children in the US

Download the full report

Download the appendices

Tlcharger le rsum et les recommandations - (Download the summary and recommendations in French)

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However, the field remains fraught with uneven, inadequate, and piecemeal standards of care and broad disagreements among practitioners over how best to respect and protect the rights of their intersex patients. While certain surgical interventions on intersex children are undisputedly medically necessary, some surgeons in the US perform risky and medically unnecessary cosmetic surgeries on intersex children, often before they are even able to talk.

The medical community has made progress in intersex care in recent decades, but medically unnecessary irreversible surgeries on children and infants remain common, said [Kyle Knight](#), researcher at Human Rights Watch and author of the report. The pressure to fit in and live a normal life is real, but there is no evidence that surgery delivers on the promise of making that easier, and ample evidence that it risks causing irreversible lifelong harm.

United Nations human rights bodies have increasingly condemned countries around the world in recent years for failing to ban medically unnecessary surgery on intersex children. In a 2013 report, the United Nations special rapporteur on torture [noted that](#), Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery leaving them with permanent, irreversible infertility and causing severe mental suffering.

In July 2017, three former US surgeons general [wrote](#) that they believed there is insufficient evidence that growing up with atypical genitalia leads to psychosocial distress, and while there is little evidence that cosmetic infant genitoplasty is necessary to reduce psychological damage, evidence does show that the surgery itself can cause severe and irreversible physical harm and emotional distress.

For decades, parents of intersex babies have been pressured into consenting to medically unnecessary and irreversible surgery to make their children appear normal.

The report is based on in-depth interviews conducted by Human Rights Watch researcher Kyle Knight and Dr. Suegee Tamar-Mattis, a physician and Human Rights Watch research consultant, with 30 intersex adults, 2 intersex children, 17 parents of intersex children, and 21 healthcare practitioners including gynecologists, endocrinologists, urologists, psychologists, and other mental health providers who work with intersex people. The report also contains an extensive literature review, and features the available data on surgeries.

Several doctors told Human Rights Watch that while they were increasingly uncomfortable advising parents to choose these surgeries, the operations are still taking place in their clinics. Parents said they still feel pressure from doctors to elect these surgeries.

The pediatricians are in a position of power. And if its an issue of parents being scared, that is the problem that has to get solved. Its not really a matter of if you do surgery that doesnt make any sense, thats not solving anything, an endocrinologist and medical professor told Human Rights Watch. When were trying to force people into cultural normative, hetero-normative situations, theres a high chance that were going to make some major mistakes and harm people irreparably, said a gynecologist on a team for differences in sex development.

Parents of an 8-year-old born with atypical genitals said: The doctors told us it was important to have the surgery right away because it would be traumatic for our child to grow up looking different. Whats more traumatic? This sort of operation or growing up a little different?

These and other parents told Human Rights Watch that the most helpful resource in raising their intersex children was meeting other parents and intersex adults through support groups.

The experience of those who have undergone the surgery, along with principles of medical ethics, suggest that unless and until there is outcome data establishing that the medical benefits of specific surgical procedures on infants and young children outweigh the potential harm, they should not be used, interACT and Human Rights Watch said. At present and despite several decades worth of surgeries, that evidence simply doesnt exist.

The US government and medical bodies should put an end to all surgical procedures that seek to alter the gonads, genitals, or internal sex organs of children with atypical sex characteristics too young to participate in the decision, when those procedures both carry a meaningful risk of harm and can be safely deferred, Human Rights Watch and interACT said.

Parents of intersex children are often scared and confused about how best to protect their children from stigma, Zieselman said. Its such a relief for them when they meet others who have the same intersex traits as their children and see that they have grown up healthy and happy.

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