

Should We 'Fix' Intersex Children?

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When Mark and Pam Crawford took their family to Great Wolf Lodge, a water adventure park, for a week's vacation, their seven-year-old made a request.

"Since we don't know anybody," S asked her parents, "can I be a boy?"

The Crawfords, who adopted S at the age of two, had seen signs for years that she did not think of herself as female.

S didn't want braided hair; S wanted a haircut "like dad's." At Halloween, S wanted to be a superhero, but not Wonder Woman. S wanted to use the men's bathroom and liked to be referred to as a boy. S already tended to be perceived as a boy by strangers, after requesting a buzz cut about a month before the family's vacation.

The Department of Social Services had told the Crawfords their child was born with an intersex condition, meaning the baby's gender was unclear. S's genitals had been surgically reconstructed to look more female.

So at Great Wolf Lodge, S's parents thought, "Okay." Maybe, the resort, where no one knew S, would be a safe place to try out being a boy.

The week went well. S picked out a new, male name "M." When the family arrived back home in South Carolina, things snowballed. M kept up his requests to be a boy, first at gymnastics class, then at the family's Jewish temple and at school. His parents helped as M told the world step-by-step what he had known all along.

In retrospect, Mark Crawford said, "He never gave us any indication that he was not a boy."

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M was born with genitals that were not clearly male or female. Also known as disorders of sex development (DSDs), the best guess by researchers is that intersex conditions affect [one in 2,000 children](#).

The response by doctors is often to carry out largely unregulated and controversial surgeries that aim to make an infant's genitals and reproductive organs more normal but can often have unintended consequences, according to intersex adults, advocates and some doctors.

A long and gut-wrenching list of damaging side effects—painful scarring, reduced sexual sensitivity, torn genital tissue, removal of natural hormones and possible sterilization—combined with the chance of assigning children a gender they don't feel comfortable with has left many calling for the surgeries to be heavily restricted.

The Crawfords are bringing a landmark lawsuit on behalf of M against the hospitals and doctors who treated M, and the South Carolina Department of Social Services, which allowed the operation when M was in foster care.

A state lawsuit against the hospitals and the South Carolina Department of Social Services alleges medical malpractice and negligence, while a federal suit accuses the individual doctors and Social Services employees of violating M's due-process rights under the 14th Amendment, which says that no state shall "deprive any person of life, liberty, or property without due process of law."

Part of what spurred the legal action, which is supported by the intersex civil rights group Advocates for Informed Choice and the Southern Poverty Law Center, is to prevent the surgery from happening to more children, the Crawfords say. But advocates have been pushing back on these surgeries since more than a decade ago.

During the 1990s, intersex adults who had received surgery as infants came forward speaking about their sense of mutilation. At the same time, an experiment from Johns Hopkins University that claimed to prove young children could safely be assigned any gender with surgical "reinforcement" was revealed to be a failure. The study had been initiated in 1967 by psychologist John Money, who claimed to have successfully given a boy female anatomy and had the child live as a girl. The child, whose penis was burnt off in a circumcision accident, was castrated and operated on to look female at the age of 22 months—eight months before the age at which Money claimed gender became fixed.

Until the 1950s, intersex children had largely been left alone, but Money's experiment provided support for early surgical intervention. However, one of Money's rival researchers tracked down his study's subject and, in 1997, showed that the child had never been happy as a girl and had converted back to living as man, sending shockwaves through the medical profession. Nevertheless, the surgeries continue.

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On April 18, 2006, when M was 16 months old, Dr. Ian Aaronson operated on him at the Medical University of South Carolina (MUSC). He reduced M's penis to look more like a clitoris, cut up his scrotum to form labia, and removed his internal testicle tissue. Two other specialists also treated M: Dr. Yaw Appiagyei-Dankah, who worked at MUSC, and Dr. James Amrhein from Greenville Hospital.

In a letter to M's pediatrician, Dr. Amrhein wrote that initially, M's condition was "confusing." He had been identified as a boy at birth because of his "rather large" penis. Routine blood tests showed his testosterone levels were extremely elevated. However, he had a small vaginal opening beneath his penis and both ovarian and testicular tissue. "Surgical correction" was necessary, the doctors noted in medical records. It took the trio about four months to decide which gender to assign M.

All three doctors and the Department of Social Services declined to comment because of the pending court cases.

"I was ... able to reassure both her social worker and her [foster] mother that as far as the external genitalia are concerned, this can be corrected surgically so that the baby looks either a normal boy or girl," Aaronson wrote to Amrhein on January 18, 2006 according to the court complaint.

Fertility is one of the factors doctors take into account when considering which gender to assign a child. Some medical literature describes children with M's condition, ovotesticular DSD, as having a higher potential for fertility by assigning them as girls and keeping their ovarian tissue.

Whether or not M's female or male reproductive organs were fertile is likely to be a contested point in the case. The legal complaint claims that the removal of M's testicular tissue removed M's potential for male reproductive function but the defendants' response denies this.

By late February 2006, Aaronson seemed to be coming to a decision based on the fact that S's foster parents were raising the toddler as a girl and the child's vagina seemed fully formed.

"My bias at the moment is towards female, although I have raised the possibility because of the substantial virilization of the external genitalia that there may have been sufficient testosterone imprinting to question ultimate gender identity," he wrote in February according to court records.

The doctors decided to do feminizing surgery in April.

Aaronson was aware of the controversy surrounding the procedure. "Carrying out a feminizing genitoplasty on an infant who might eventually identify herself as a boy would be catastrophic," he wrote [in a medical journal](#) in 2001. He acknowledged the arguments that surgery on infants should be postponed, but concluded, "most parents are disturbed by the appearance of the genitalia and request that something be done as soon as possible so that their baby 'looks normal.'"

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There is a vacuum of reliable data tracking the number of surgeries performed on intersex children. The few figures that exist reinforce the doctors and medical literature that describe the surgeries as continuing.

A government database, the [Kids' Inpatient Database](#) (KID), suggests that in 2006 there were 139 clitoral reduction surgeries—the same operation that reduced M's penis. This was a drop from 1997 when there were 204 procedures, but the estimated number then rose to 156 in 2009. KID data is compiled from estimated averages from a sample of more than 2,500 children's hospitals but for rare conditions like DSD, the margin of error is high.

Dr. Arlene Baratz, a medical adviser and board member of the Androgen Insensitivity Syndrome-Disorders of Sex Development (AIS-DSD) Support Group, one of the country's largest organizations for families of intersex children, said she was concerned that the medical recommendations parents received seemed inconsistent.

"Each doctor is saying something different in cases that we would view as pretty similar," she said. "At some hospitals there's a lot of pressure. Others are more flexible and encourage parents to take more time making decisions on irreversible procedures."

Aliya, a mother of 10-year-old twins in Florida described the challenge of being caught in the crossfire of medical opinion.

"I can see how people can be swayed," she said. "They led me to question myself because of how adamant they were."

When Aliya's children were born, her son weighed only one and a half pounds and had a very small penis. His urethral opening was near his perineum, not the tip of his phallus.

Multiple doctors told Aliya that she should do surgery immediately. The first time was in the hot, bustling, intensive care unit at the University of Florida where she was uncertain whether or not her son would live. A doctor Aliya didn't know recommended that she raise her son as a girl. Then, after the baby's condition had stabilized, a surgeon told Aliya that she should allow him to operate to make her son's penis appear more normal, "if you want your child to be a real man."

By that stage, Aliya had researched some of the risks of the surgery—urethral tissue that is unable to withstand urine and becomes damaged; nerve impairment; scar tissue; loss of sensation. The surgeon acknowledged these complications when Aliya raised them, but she says he didn't want to discuss them. Fearing her son "might come out of surgery worse off than he went in," she walked away.

When he was seven, she told him about the operation. "I like my penis just the way it is," he said, and hasn't brought it up since.

Amber, a mother based in Arkansas, described herself as "furious" that she allowed her daughter's internal gonad to be removed during an exploratory procedure. While Amber's eight-week-old baby was on the operating table, the doctor said that what he found might cause cancer, and he needed Amber to sign off on removing it.

Her daughter, now six, was born with a DSD called Complete Androgen Insensitivity Syndrome (CAIS), meaning she has XY chromosomes but her body does not process testosterone. People with CAIS look like and typically identify as women, but have internal undeveloped testes. These contain germ cells that some specialists theorize could be used to contribute to an embryo, making people with CAIS potentially fertile with the help of reproductive technology. These gonads also produce hormones the body converts into estrogen.

Amber later realized from further research that the risk of cancer was probably similar to the chance of a normal woman developing breast cancer.

"I don't plan to lob off one my daughter's breasts because there's a chance she'll get breast cancer," she said. "They robbed my daughter of half of a chance to have a natural puberty."

Now that he is nine, M sometimes asks his parents questions like, “When will I grow a penis?”

“We’re always really matter-of-fact about it,” Mark Crawford said. “He gets sad as he realizes more and more what has happened to him.”

Chances of assigning a child the wrong gender vary depending on the intersex condition.

M was born with a relatively rare intersex disorder called ovotesticular DSD, which doctors say makes it particularly difficult to predict gender.

One of the more common DSDs, Congenital Adrenal Hypoplasia (CAH), is often considered by doctors to be a safe bet for predicting female gender. But even children with CAH end up identifying as boys in between 5 and 10 percent of cases, according to researchers. Based on these figures, opponents of surgery point out that in one operation out of 20, doctors are cutting off a little boy’s penis. But the risk of assigning the wrong gender, along with other outcomes of surgery, has not been definitively quantified with long-term controlled studies and large sample sizes.

“If you don’t have data, it’s left to people’s subjective opinions,” said Dr. Douglas Husmann, a pediatric urologist at the Mayo Clinic.

Dr. Barry Kogan, the president of the Society for Pediatric Urology, said that for more extreme cases of genital difference, “it’s really easy to say [that] the outcomes of surgery are not as good as you think they are, but we don’t know the outcomes of not doing surgery.”

Husmann said he tries to give parents an unbiased opinion that presents the risks and benefits of surgery. Privately, he believes there could be negative consequences of not operating. Four of his patients who didn’t have surgery were “ostracized,” he said, after they were seen naked in locker rooms at school. Some of these families had to move cities for their children to start over, he said.

“I’m frustrated by the good work that’s been questioned by the vocal minority, who in my opinion wouldn’t be happy in any gender,” said Dr. Howard Snyder from the Children’s Hospital of Philadelphia.

He said that most of his cases, between 7 and 10 a year, were children with CAH. Although he is aware of studies in which some children later identified as boys, Snyder says those sample sizes were “a drop in the bucket” and don’t match up with the observations of his patients. Holding off on operating, he says, is “simply unrealistic.” Not every parent shares this sentiment.

“We’re very fortunate that our son didn’t have a situation like M,” said Marie, a mother of two children with DSDs from the East Coast.

Her nine-year-old son, adopted from Asia, has a condition called gonadal dysgenesis. Marie and her partner brought him home as a little girl, but he gravitated toward boys’ clothing, and haircuts, and asked at the age of five to live as a boy. If he were operated on as an infant, he would have missed out on having a penis.

Meanwhile, Marie’s daughter, who is 12, had her genitals surgically reconstructed to look more feminine in a medical center in Asia, before she was adopted at age two. One day when the girl was six, she left the living room where she was playing to use the bathroom. Marie suddenly heard her yell. “Ow, Mom, ow.” She rushed into the bathroom and found her daughter crying, stuck on the toilet.

Marie coaxed the screaming child onto the floor and opened her legs to figure out what was wrong. The girl's vagina, which had been a one-centimeter opening, was now four centimeters of red, open wound, "stinging and hurting and scary."

Marie took her shocked and silent daughter to an emergency medical appointment. It was confirmed that as the little girl had grown, the tissue in her vagina, which was inserted during her operation, was not stretching at the same rate as the rest of her body, and had ripped.

Luckily, the wound had torn cleanly. Marie took her daughter home; it took a month to heal.

About a year later, nerve endings emerged at the surface of the girl's vagina, forming sensitive nodes. She could not ride a bike, struggled to wipe herself with toilet paper and avoided restrictive pants like jeans. The nodes reduced after she turned nine, but she is still "hypersensitive" around the groin area, according to Marie, and refuses to wear clothing like skinny jeans that are popular with the other girls at her school.

Vaginoplasties are widely acknowledged by surgeons to have a high risk of stenosis—the narrowing or loss of flexibility of the vagina, often accompanied by scar tissue. There are also fears that some surgeries, in particular those the clitoris, will reduce sexual sensation. Surgeons say their new techniques spare nerves, unlike the older, outdated procedures.

"It's safer than it used to be," Husmann said. "Do we have adequate tests on sensitivity? It's very difficult to do those tests."

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"M and his supporters clearly do not agree with what has long been the dominant treatment plan for children born with intersex conditions," states Amrhein's brief in the appeal of the federal court's decision to accept M's case.

This is why in the past it has been difficult to bring legal action against doctors for performing surgery on intersex people: because the standard of care to which medical professionals are held consists of the actual practice of doctors. With such a long history of medical intervention, many legal experts, doctors, and bioethicists say that decisions to operate on intersex children are likely justified in many cases, despite the concern some have over surgeries.

A [consensus statement](#) by doctors from 2006 addresses the treatment of children with DSDs. And in its [report on torture last year](#), the Special Rapporteur to the United Nations' Human Rights Council called on member states to end laws allowing "forced genital-normalizing" surgeries on intersex people.

In the United States, guidelines and statements made by medical professionals on areas of consensus are strong evidence for what the standard of care is considered. The 2006 statement does call for caution on surgeries in some situations, but some doctors and bioethicists call it vague.

Dr. Charlotte Boney, a professor at Brown who refuses to allow clitoral reduction surgery at Rhode Island Children's Hospital where she practices, said the 2006 statement, "didn't go far enough. It leads you to believe surgery is a viable option. If you read it, you would never know there's a huge battle, an ethical dilemma, and potential harm."

The lack of strong scientific evidence either way is the reason the guidelines will not be made more restrictive at this stage, according to surgeons. A working paper drawn from a group of leading pediatric urologists, did a [comprehensive literature review](#) in 2012.

“It is clear that outcomes studies lack the necessary detail to base further recommendations upon,” they wrote.

M’s case takes a different route. The fact that he was in foster care and treated in state-run hospitals allows the federal court case to claim a breach of his constitutional rights. The case has been accepted by the district court to go to trial, but the decision is being appealed. If M’s case is successful, it may set a precedent that surgery on intersex children is unconstitutional in at least some situations, such as when it is very difficult to predict gender. This would not apply to many doctors, who do not practice in state hospitals and have to have the consent of a child’s parents to operate. But legal experts say it would influence public opinion and send a strong message to doctors and hospital ethics boards.

M’s thoughts of the future now involve wanting to be a firefighter or fixing cars, but the Crawfords anticipate his teenage years will be “tough.”

“It’s difficult for everyone,” Mark Crawford said, but M will have added challenges. He will have to start hormone replacement therapy and, without a penis, will become aware, “that there is this life of sexual behavior that he’s not able to participate in.”

“The real intent of the lawsuit is just to uphold these constitutional principles—integrity of a person’s body and some kind of due process for infants where people around them in power are considering doing surgeries like this,” Mark Crawford said.

“I would give anything for this not to have been done to our child,” Pam Crawford said. “I want to see that his suffering will not be entirely wasted.”

** This piece originally stated that the Crawfords decided to do feminizing surgery on M, rather than the doctors. We regret the error.*