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Between The Sexes

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More babies than you might think are born neither boys nor girls. Sorting it out is a lifelong struggle

In 1993 Debbie Hartman was sure she was hearing things in her hospital room. She had just undergone a caesarean section, and the doctors were saying the baby was healthy but they weren't sure whether it was a boy or a girl. "I thought the drugs were making me hallucinate," she recalls. In fact, she was hearing just fine. But nothing about her child's biology — from the chromosomes to the reproductive tissue — conformed to the standard demarcations we have come to expect between the male and female sexes. In the language of developmental biologists, the baby was "intersexual."

Careful examination showed that the infant had one testis, what looked like a small penis and no uterus or vagina. Genetic tests did not make things any clearer: some of the child's cells contained the XX chromosome pairing typically seen in girls, others contained the XY pattern seen in boys, and some had but a single X chromosome, commonly seen in girls with a condition called Turner syndrome.

Technically speaking, the Hartman baby was a true hermaphrodite. Scientists don't know how this happens, but one possible explanation is that two eggs are fertilized in the womb — one XX and the other XY — but rather than developing separately into twins, the zygotes merge to become one embryo. At any rate, "hermaphrodite" is not one of the options available on a birth certificate, so the Hartmans' doctors struggled to figure out which sex was more appropriate for the child. Meanwhile, Debbie's sister and mother told relatives and friends not to send anything pink or blue. "They said yellow or green," Hartman recalls. "Or better yet, just send a card." After two weeks, the doctors decided the baby was a boy. Debbie and her husband — they have since divorced — named their son Kyle and took him home. Debbie quickly dubbed her little guy Mr. Man and Slugger. When Kyle was 11 weeks old,

however, he developed a hernia that required surgery. Midway through the operation, four doctors came to the waiting room, and one of them told Kyle's parents that "your child is in fact a girl." The surgical team had found rudimentary ovarian and Fallopian-tube tissue in Kyle's body.

In some ways, this latest turn of events was even more upsetting and confusing than the birth. But the physician's recommendation was clear: the vestigial ovarian and Fallopian-tube tissue and the testis should be removed at once, while the child was still under anesthesia. Otherwise the tissue could become cancerous. "All I could hear was cancer, cancer, cancer," Debbie says. So she and her husband consented to the operation. (The phallus, which doctors eventually renamed a clitoris, was surgically reduced two years later.) The next day the Hartmans took home their recovering infant, whom they quickly renamed Kelli. The family held a second baby shower, and boyish clothing was replaced with lacy pink dresses and other feminine attire.

Kelli went on to have three more surgeries to construct female-looking genitalia. But the matter wasn't settled. At the age of 4, she started asking, "Mommy, am I a boy or a girl?" When she was 6, she questioned her mother about all her surgical scars, and when Kelli was 8, her mother told her the whole story.

The truth came as a relief, although Kelli, now 10, is still grappling with the significance of gender in her life. A stocky, surefooted kid whose interests range from gardening and landscaping to marble collecting and woodworking, Kelli suffers from attention-deficit/hyperactivity disorder, which, she says, actually makes her feel more self-conscious than being intersexual. When asked what she wants to be when she grows up, she replies, "A carpenter. Maybe I'll be a male carpenter." Why a male carpenter? "Because I'd be taken more seriously."

True hermaphrodites like Kelli are thought to be quite rare. But less extreme cases of intersexuality occur more often than you might think. One estimate from a scientific review published in 2000 is that they represent 0.2% to 2% of live births. About 30 genetic and hormonal conditions can give rise to intersexuality, leading, in some folks, to an obvious mixture of male and female sex traits. In others the variation is far less noticeable, producing, for example, the premature development of body hair. Indeed, many intersexuals probably live their whole lives as men or women without ever suspecting the complexity of their nature.

For years doctors believed that the best treatment for an obviously intersexual newborn was a swift one. The reproductive system and genitalia were surgically refashioned to conform to one sex or the other. (In practice, this often meant

deciding that the child should be a girl because, in the indelicate phrasing of the surgical world, "it's easier to make a hole than build a pole.") The goal was to minimize the amount of time the child spent with a nonstandard body in the hope that he or she would find it easier to develop a conventional sense of gender. As in Kelli's case, there was also concern that "extraneous" reproductive tissues might be more likely to become malignant.

In recent years, however, the need for swift and irreversible intervention has been called into question. Adult intersexuals are stepping from the shadows to talk about their experiences, including the harmful effects they attribute to extensive childhood surgery. Some complain that they were assigned the wrong sex at birth. Others are more upset about the secrecy and shame their condition often elicited from their family. There is growing evidence that such surgery can interfere with the ability to achieve sexual gratification, that it can cause chronic incontinence and that the cancer risk may be exaggerated.

As these issues have emerged, the American Academy of Pediatrics (A.A.P.) has begun to reconsider its policy of endorsing early surgery for intersexuals. Dr. Ian Aaronson, a professor of urology and pediatrics at the Medical University of South Carolina, who helped write the A.A.P. guidelines, is coordinating what he hopes will be the largest-ever follow-up study of intersexuals to see what effects, good or bad, surgery has had on their emotional, psychological and sexual well-being.

Nobody is arguing that babies should be raised without a gender identity, says Dr. Bruce Wilson, a pediatric endocrinologist at DeVos Children's Hospital in Grand Rapids, Mich. "Those decisions should be made reasonably quickly, within a few days," he believes. But in his view and that of a growing number of other doctors, surgery can often be postponed until closer to puberty or even later, when the child can more effectively participate in the decision and help ensure that the surgically fashioned gender fits the child's subjective sense of self.

There is a larger social issue to consider. Despite the many changes in gender roles in recent decades, our society is still fixed on the idea that there are just two separate sexes. Is the rush to early surgery a matter of medical necessity, or is it a matter of social bias that leaves doctors and parents uncomfortable with nonstandard genitalia? It's a question that more intersexuals are raising. "Doctors have found a medical solution to what is essentially a social problem," insists Thea Hillman, board member of the advocacy group Intersex Society of North America (<http://www.isna.org/>). "The problem has to do with differences and people's fear of differences."

Yet postponing surgery would carry its own burdens. "When children become aware of their body image at age 2 or 3 and compare their anatomy with others', questions are raised about the potential for psychological harm through their childhood," Aaronson says.

Either way, the decision to operate soon after birth isn't easy. In retrospect, Kelli's mom thinks she might have waited. "Parents can help their kids live with genitals that are different," she says. On the other hand, she acknowledges, postponing surgery might have been difficult too. "If we had left Kyle as Kyle, I'm convinced he would have felt feminine at times."

Part of what makes the decision so complex is that even when the chromosomes present a clear message on gender, anatomy may contradict it. Consider Sherri, a 45-year-old tax attorney from San Diego. Although her sex chromosomes are unambiguously XY, there is no doubt that she is a woman. Sherri has androgen-insensitivity syndrome (AIS), a condition that affects prenatal development. All embryos start out with the rudiments of male and female reproductive systems. A sort of developmental tug-of-war ensues until, generally speaking, the male reproductive system predominates in XY fetuses and the female in XX fetuses. The external male genitalia will not take shape in an XY fetus, however, until after the embryonic testes form and begin to produce testosterone.

AIS occurs when a gene on the X chromosome prevents the fetus from responding to that prenatal testosterone. Because the genitalia cannot be masculinized, they assume a more female structure. But that's not all. In the complete form of AIS, the body cannot respond to testosterone at all and the baby develops as a female, although without a functioning reproductive system. When Sherri was 11, she was told that she could never bear children because she had been born with "twisted ovaries" that had to be removed when she was a baby. In fact, the "ovaries" were her testes. "No one ever explained to me what my medical condition was," Sherri says.

The secrecy that surrounds intersexuality may be the most damaging thing about it. Julianne Tutty, a 35-year-old assistant deli manager in a Boston supermarket, didn't learn she was intersexual until she was 31. During a routine visit to her doctor's office, she became curious about her voluminous medical records and decided to sneak a peek. They indicated her chromosomes are all XY, yet she was born with an internal vagina, two testes and a "flattened stump" for a penis. "I was stunned," she says. Eventually Tutty got a copy of her medical records. "It was like getting the missing piece of a jigsaw puzzle."

Tutty's parents never told her she had undergone surgery as an infant to make her

more female in appearance. Looking back, she thinks they made the right decision but wishes they had been more forthcoming. Since discovering her intersexuality, Tutty has decided to stop dating men. "I had this fear that if the truth about me came out, things could get ugly," she says. For nearly a year, she has been happily involved with a woman. "Things have turned out well for me," Tutty says. "A lot of intersex people never feel O.K. in relationships or even find partners."

Relationships are one thing, but even everyday paperwork can be a problem. Elijah Hobbs, 26, was raised as a girl in Cicero, Ind. At puberty, his body developed both feminine and masculine features — breasts but broad shoulders and a deep voice. It became more difficult to pass as a girl, and Hobbs eventually came to think of himself as male. At 24, he legally changed his sex to male, and in January he underwent surgery to have his breasts and ovaries removed. To get medical coverage, he told his insurance company he was a woman. After all, what guy would require these operations?

Elijah, Julianne and Sherri all would have found life easier if less embarrassment and secrecy were associated with their condition. That's a goal the Intersex Society is working toward. Meanwhile, scientists hope that more sophisticated testing will eventually help doctors and families make more informed choices about how to treat intersexuals. New research on the genetics of sexual development shows, for example, that several of the genes that influence sex are not even located on the X or Y chromosomes. What it all boils down to, says Dr. Eric Vilain, a professor of human genetics, pediatrics and urology at UCLA, is that the roots of gender identity are much more complex than anyone thought. But Kelli could have told them that.