

MEDICINE

# Gender Limbo

For 40 years surgeons have been 'correcting' some babies' ambiguous genitals. As adults, the patients don't always like the results.

BY GEOFFREY COWLEY

HEIDI WAS A HEALTHY, full-term baby when she poked her head into the world on Oct. 20, 1961. But the world wasn't sure what to make of her. Instead of congratulating Heidi's 19-year-old mother,

the delivery team kept her sedated for several days and wrestled with a baffling question: was this a boy or a girl? The baby had a penis, but it was extremely small, and the urethral opening was down near the base. There was also a scrotum, though the testes hadn't descended to fill it. Blood tests showed that the child was genetically male. But the doctors worried that a boy with such unusual genitalia would never fit in. So they declared Heidi a girl, and recommended surgery and hormone therapy to ensure that she developed normally. "My mother said she wanted to take me and run like hell," she says now, "but the doctors implied that unless they made me look like other girls, I

“ ‘After surgery you'll be normal,’ the doctors always tell us. ‘You'll be a girl like other girls.’ Never mind that for months they had been saying I'd be a boy like other boys.”

— KIRA TRIEA

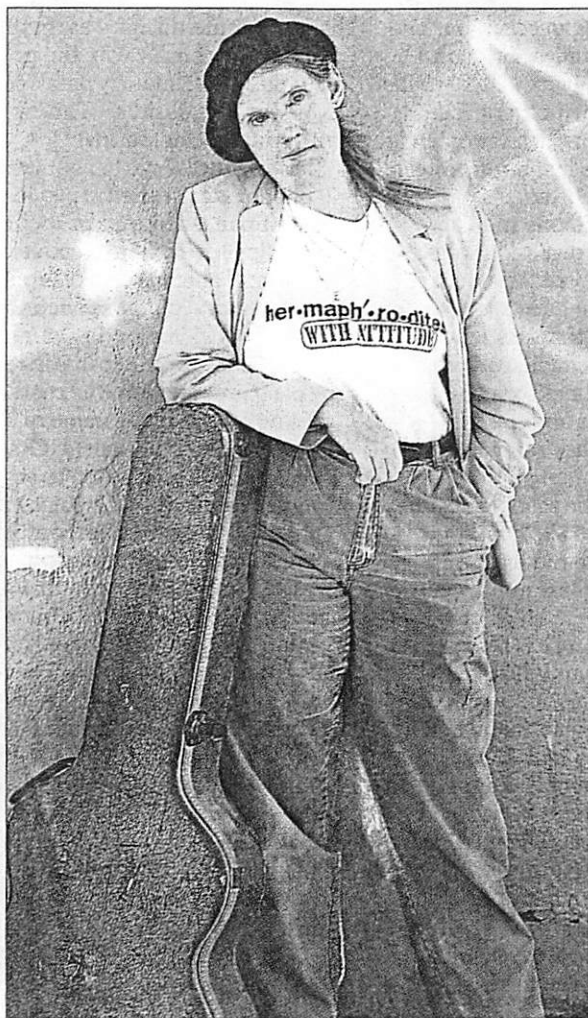
would be an outcast and commit suicide.”

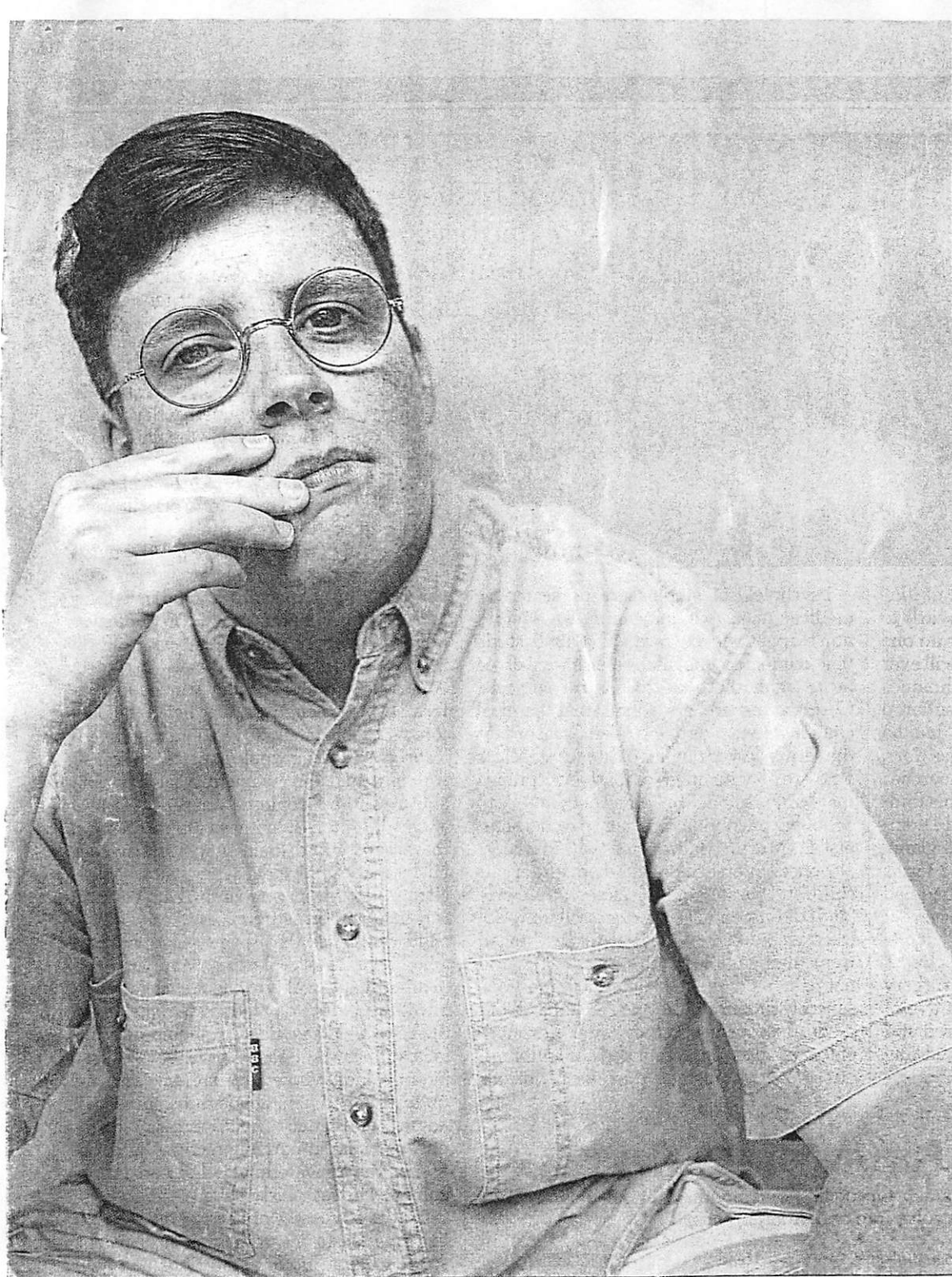
Heidi has in fact contemplated suicide many times—not because she's different, she says, but because of the unrelenting efforts to make her normal. When she was 3 months old, doctors opened her belly to inspect her reproductive system. At 7 months, they went back in to remove her ill-formed testes. As a 5-year-old, she returned to the hospital for an overnight stay and woke up with what she recalls as a painful itch between her legs. "When I asked the doctor

where my thing had gone, he said, 'We had to take it off because you want to look like the other little girls in your class.'" She took the feminizing hormones she was given as a teenager, but when her doctors suggested creating a vagina, she balked. "You eventually decide you're not going anywhere near needles, scissors or scalpels," she says. Today Heidi lives as a lesbian. But she has never had an orgasm (she likens a lover's touch to 40-grit sandpaper)—and she is bitter. "Sometimes I get so mad I want to get a dull, rusty knife," she says, "and start hacking off doctors' genitals."

Heidi wasn't a victim of medical renegades. The protocol her doctors followed has been standard practice for 40 years. Every month, dozens of sexually ambiguous newborns get a "gender assignment" (usually female) and a surgical operation to confirm it. But the practice is now under attack. Members of a fledgling gender-identity movement are crusading to stop the surgical juggernaut. And though they lack political clout, they're exposing flaws in a cherished medical doctrine. Most physicians still adamantly defend the practice of "correcting" ambiguous sex organs. They say the operations are usually successful, especially with current techniques. Unfortunately, there is little if any research to back that assertion. "We need to know the long-term effects of these procedures," says Dr. Justine Schober, a pediatric urologist in Erie, Pa. "And the truth is, we don't."

Fetal development is a complicated business, but it usually follows one of two paths. If a fetus is genetically female (having two X-shaped sex chromosomes), its gonads mature into ovaries. In genetic males





“When I talked to doctors about meeting other families and other children, they told me it would be impossible, that it would be a terrible idea. But it was very healing.”

—JUDY (MAX) BECK

some societies, revered in others. But until 40 years ago, no one gave much thought to “fixing” them. That changed in the mid-1950s, when sex researcher John Money and his colleagues at Johns Hopkins Hospital hypothesized that sexual identity was like language—easily acquired, but only during a critical period in early childhood. In the hope of creating better lives for intersex children, the Hopkins team started remodeling their genitals and coaching their parents to raise them accordingly. The specialists’ optimistic case reports wowed the profession, and surgery soon became the norm. Even now, despite all the controversy, the American Academy of Pediatrics (AAP) maintains that kids with ambiguous genitalia “can be raised successfully as members of either sex” and recommends going ahead with surgery within the first 15 months of life.

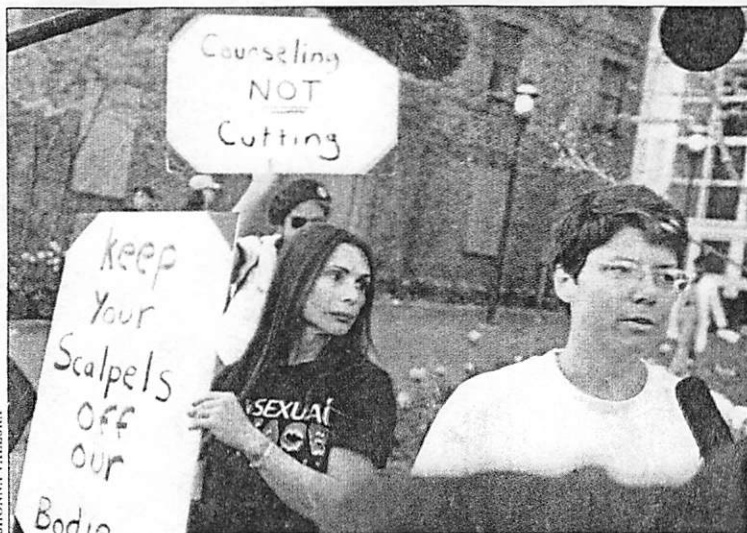
(who bear an X and a Y), the same glands develop into testes. The basic tendency of any fetus—XX or XY—is to become anatomically female. But as the testes of an XY baby start churning out testosterone, the child gets a chance to masculinize. If the hormone reaches the right tissues in the right forms, the developing labia will fuse to create a scrotum and a penile shaft, and the budding clitoris will swell to form the glans, or head, of the penis.

The process isn’t always so tidy. Though no one has hard numbers, experts suspect that roughly one baby in 2,000 is born with sex organs that don’t fit either of the standard categories. Most fall into one of three

basic groups, which Brown University biologist Anne Fausto-Sterling has dubbed herms, fermes and merms. Herms, or true hermaphrodites, have both testicular and ovarian tissue, often as a result of abnormal chromosomes. Fermes—technically, “female pseudohermaphrodites”—are genetic females whose external sex organs become partly masculinized through prenatal exposure to testosterone. And merms, or male pseudohermaphrodites, are genetic males who *don’t* fully masculinize in the womb, either because they don’t produce the necessary hormones or because their tissues don’t respond.

Intersexuals have been persecuted in

tal anomaly interferes with urination or creates a risk of infection. But many specialists believe that creating a normal appearance is almost as urgent. Dr. Antoine Khoury, chief of pediatric urology at Toronto’s Hospital for Sick Children, considers genital ambiguity a “hidden disease” that can be cured with modern, nerve-sparing surgery. To bolster the point, he produces a letter from the mother of a 17-month-old ferme he treated at 6 months for fused labia and an enlarged clitoris. Another physician had seen that the child’s chart mentioned a previous surgery. “I told [the doctor] about the procedures performed by you,” the mother writes, “and she



SHONNA VALESKA

“I’m sure surgeons believe we’re fine because we’ve been silent for so long, but silence is no sign of healthy sexual function. It’s a sign we’ve been shamed.”

—CHERYL CHASE

commented that she could not tell *at all*.”

That child may benefit, but it’s too early to declare her operation a success, for no one knows whether her bobbed clitoris will ever function normally. “The new techniques may cause less scarring than people suffered 20 years ago,” says Fausto-Sterling, “but the claims are based on hope. No one has done follow-up studies.” Actually, one researcher did run a small study recently, and his findings weren’t encouraging. Dr. David Thomas, a pediatric urologist in Leeds, England, had a team of specialists examine 12 ferns between the ages of 11 and 15 who had had their vaginas opened and their clitorises reduced during infancy. Most had been treated by specialists in state-of-the-art clinics. Yet every child had required further surgery to maintain a vaginal opening. And five of the 12 reduced clitorises had withered and died, even though several had looked fine following surgery.

Psychological studies are as scarce as medical ones, but outcomes like Heidi’s don’t appear to be rare. In a 1995 study that compared the life experiences of 44 ferns with those of 20 control subjects, German researchers found that surgical complications were the main reason for the ferns’ lower quality of life. Counselors who work with intersex patients confirm that impression. In a recent letter to Schober, Sacramento, Calif., psychotherapist H. Martin Malin notes that, in his experience, intersexuals who had surgery as children “became quite isolated at puberty [and] did not integrate successfully into society as adults.” Many were “estranged from their families,” he wrote. “They did not pair-bond; their sexual functioning was severely impaired; they were phobic about medical procedures; they were despondent and had contemplated or attempted suicide.” Finally, “they were furious

she says, “but I knew it was a terrible thing and upset my mother a lot. The guilt was killing.” Cheryl Chase, the 41-year-old director of the Intersex Society of North America, says she not only was denied information as a child but was lied to by doctors when she later tried to obtain her medical records. “The whole experience was so traumatizing and shameful that I wasn’t able to talk about it until I was 35.”

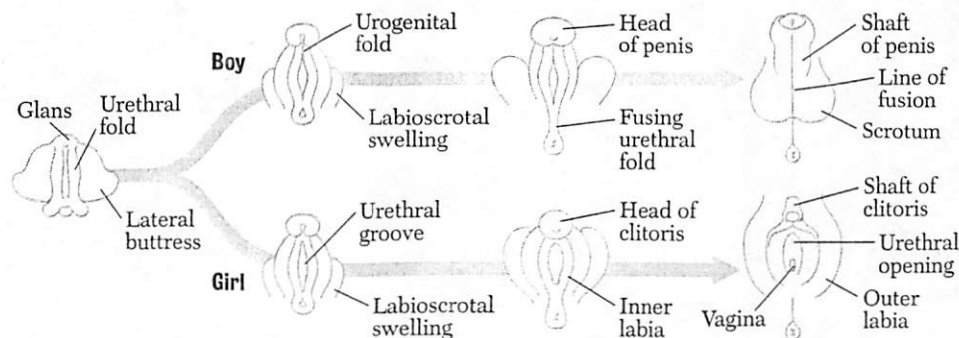
Despite their sometimes angry rhetoric, the activists and their supporters have a fairly modest agenda. They want physicians to delay surgery until their patients can make informed choices. “You raise a child in the sex that seems most comfortable,” says Fausto-Sterling, “and you keep in mind that their body might change somehow.” And instead of fueling parents’ fears, the reformers say, doctors should offer information and support. Studies suggest that intersex kids who escape surgery can fare quite well. When Schober examined 12 adults with intact “micropenises,” every one of them reported erections and orgasms. Seven were married or cohabiting, and one had fathered a child.

To the advocates of early surgery, waiting for kids to make their own decisions sounds like a moral abdication. “We will make some mistakes in gender assignment,” says Dr. Kenneth Glassberg, the Brooklyn pediatric urologist who speaks for the AAP on the issue. “But surgery is not a disservice to the majority of intersex children. The disservice is in scaring patients away.” Dr. Heino Meyer-Bahlburg of New York’s Columbia Presbyterian Hospital agrees. While conceding that there are “very little data” and claiming he is “into empirical data, not beliefs,” he says the “persistence of gender ambiguity” is so harmful to children that “we nevertheless have to act.” Unfortunately, their patients may someday wish they hadn’t.

With THEODORE GIDEONSE and ANNE UNDERWOOD

## Male and Female: Parting of the Ways

Boys’ and girls’ genitals look very similar for the first two months after conception. But hormones gradually cause them to evolve into two different forms.



**5 weeks:** During the early weeks of gestation, male and female embryos have identical genital structures.

**7-9 weeks:** At the earliest stages of sexual differentiation, the boy’s urogenital fold begins to elongate.

**11 weeks:** The same tissue that forms a female’s inner labia produces a penile shaft in the male.

**Near birth:** The labioscrotal swelling has fused to create the boy’s scrotum and the girl’s outer labia.

SOURCES: TORTORA, “HUMAN ANATOMY”; MOORE AND PERSAUD, “BEFORE WE ARE BORN”; DIAGRAM: CHRISTOPH BLUMRICH—NEWSWEEK