

Born Between Two Sexes

This year 2,000 babies--most of them little girls--will undergo invasive surgery to "correct" their sex parts. **Jen Phillips** lets you know what the nascent intersex movement--led mostly by dykes--is doing about it.

In 1956, and after three days of debate, Cheryl Chase's parents named their newborn Charlie. But at eighteen months, doctors discovered that in addition to what they thought was a small penis with an opening along the bottom, Charlie had a uterus and ovaries. In part because the ovaries were functional, and thus potentially able to produce children, the doctors decided to make Charlie into Cheryl. As part of the procedure, they removed her entire clitoris, leaving her without orgasmic response.

No one talked about the baby's sex change. Like homosexuality--which at the time was still regarded by the medical establishment as a mental disorder--it was a verboten topic. Cheryl herself didn't know until she was twenty-one and dug up her medical records that she had been born intersexed, meaning, with genitalia that doctors decided weren't standard male or female equipment.

Chase isn't the only one with a childhood horror story. One or two children out of 2,000 are born intersexed. Over the course of this year, 2,000 surgeries will be performed in the U.S. on infants to "normalize" their genital appearance. The vast majority of surgeries are done to girls with large clitorises and--less frequently--to boys with small penises who are reassigned as female. In the case of Gaby Tako, who was born in the Bronx in 1960, her surgery was deferred until she was thirteen. Then her fused labia were split, her vagina extended, and her extended clitoris buried under a layer of flesh. "I felt dirty after the surgery," Tako told Ms. magazine. "My genitalia were never painful before, but since then, to one extent or another, they've been a source of pain." Now living as a lesbian, Tako regrets her "forced feminization." Other girls have endured daily dilations to keep open their newly created vaginas, repeated cosmetic surgeries, and most of all, the shame of knowing that an unspeakable "something" is wrong with their bodies.

This seemingly impregnable wall of secrecy that surrounds intersexuality motivated Cheryl Chase to form the Intersex Society of North America (ISNA) in 1993. "ISNA literally started in Cheryl Chase's kitchen," says Alice Dreger, an associate professor at Michigan State University's Center for Ethics and Humanities in Life Sciences and author of *Hermaphrodites and the Medical Invention of Sex*. Monica Casper, Chase's successor as executive director of the Seattle-based ISNA, concurs: "Before Cheryl started, there was no public discussion of intersex issues." Though the woman who was once a little boy named Charlie had broken the wall of silence, no one knew if it would be enough to change the long-established medical protocols.

A PROGNOSIS OF SECRECY AND SHAME

In the case of a potentially intersexed newborn, currently the American Academy

of Pediatrics advises its members to test the newborn's chromosomes, visually examine the genitalia, and scan for misplaced ovaries or testes. However, even the AAP admits that "appearances are deceptive" to some extent these criteria are arbitrary." As a result, in many cases doctors may assign newborns the wrong sex, leaving the adult patient confused and at odds with her or his sex. In addition, doctors often don't offer peer support, reliable information, or conduct follow-up visits, so patients are effectively cut off from asking questions, learning more about their bodies, or even knowing that they were born different. "Many women don't know they have anything different until they reach sixteen and go to the gyno," says Dreger. In a 2002 report from the Johns Hopkins Children's Center, only half of the intersexed adults had a "good understanding" of their condition. "Medicine is not the quick fix it's been shown to be," says Dreger. "These are not just medical problems: they're social and ethical issues."

Forty-six-year-old Janet Green, who lives in New Jersey with her children, is one of the growing number of individuals dedicated to taking care of the emotional and psychological needs of intersex individuals. Green founded Bodies Like Ours, an organization that intentionally doesn't use the word intersex because "it's too invasive. We're much more of a group that's interested in helping adults with bodies like ours accept and understand who they are, not as a medical phenomenon, just as people." Green, who is a lesbian and has Congenital Adrenal Hyperplasia (CAH), one of several medical conditions associated with intersexuality, is especially dedicated to keeping intersexed children whole. To the many doctors who feel that a child with ambiguous genitals will endure unjust schoolyard trauma, Green counters, "Kids are cruel. Kids tease about all kinds of things... if you're honest with the child, explain that they're different, and teach them to have pride and modesty; they're not frightened of it." Similar to the gay movement's position on homosexuality, Green feels that the problem lies in society's treatment of an individual's difference, not in the individuals themselves. Because "the old [medical] protocol is shame, secrecy, and isolation," Bodies Like Ours hopes to take intersexuality out of the medical realm and put it into the social and psychological. "Surgeons don't fix intersexuality because they also don't fix our brains. Surgery creates a very big problem."

FROM ISOLATION TO IDENTITY

"It's important to see a person who doesn't have shame," says Thea Hillman, a queer San Francisco performance artist with CAH. For her, "performance is the opposite of shame and secrecy." An acclaimed artist and author of *Depending on the Light*, Hillman certainly has had her share of being open. In part, she says, it's due to her progressive upbringing. "My parents were very supportive and always wanted me to embrace the way I was different." Hillman became chair of ISNA's board of directors in January of this year. Hillman, like her fellow activists at ISNA and Bodies Like Ours, stresses the need for parents of intersex children to have support groups.

At present, many of the parents' groups are organized around the individual conditions of their children. There's a group for parents of kids with androgen insensitivity syndrome, a group for parents of CAH girls. "It's very informal right now," says Alice Dreger, who serves on ISNA's board. "A lot of them exist only by word of mouth." Some of the groups, like Klinefelter Syndrome and Associates, are run by homophobic parents who are, in Dreger's words, "still buying into the belief that medical treatment will make things go away." Since the advent of ISNA and the Internet, progressive resources for intersex adults and parents of intersexuals are much easier to find than they were. Doctors "kept us purposely isolated from each other," says Green. But now anyone with a modem can Google intersex and research it on their own.

The gay community has also been seen as a source of emotional support. Many Pride festivals have already added an I to the current LGBT, and many others are on their way to doing the same. Though intersexuality is quite different from homosexuality--"when LGBT babies are born they're not at risk of medical intervention," Hillman reminds us--they both suffer from the medical establishment's homophobia. There's still a medical view, says Dreger, "that a boy with a small penis will end up gay, and that's clearly a failure in their eyes." The same fear holds true, she says, for girls born with large clitorises--that is, that they'll grow up lesbian.

Most likely, this shared sense of oppression is what makes the queer community a safe space for intersex adults. "The NGLTF's Creating Change conference was happy to have ISNA participate," says Hillman, and "some of our biggest allies have been LGBT people. That's where our first grants came from." Gay visibility and even Will & Grace's popularity has opened minds. "My students realized that being gay doesn't make you a monster," Dreger reports, "just like being intersex doesn't make you a monster."

Plus, it turns out--and probably for reasons more complex than the lesbian-big-clitoris theory--intersex people have a much higher chance of turning out to be queer. Particularly, says Monica Casper, "we know that girls with CAH are much more likely than other girls to grow up to be lesbian, but we are not sure of the exact numbers." No one, even doctors, knows exactly why women with CAH have such a high rate of lesbianism. Some think it's a result of the virilizing "bath" of male hormones that CAH fetuses receive in utero. This extended exposure to androgen often causes an enlarged clitoris, a closed vagina, and "tomboyish" personality traits later in life. But others conjecture that it's not about biology. Many non-intersex women, after all, also end up lesbian, and it's important to note that there are intersex-related conditions other than CAH in which heterosexuality is more prevalent. This leads some activists to believe that the link between intersex and lesbianism is a social one. As Casper puts it, "The LGBT community understands what it's like to be different in a world that tries to normalize everybody." (If the intersex community has a high proportion of homosexuals, it is also predominantly female. Most likely this is due to the fact

that more intersex babies are assigned female than male because, as one Johns Hopkins doctor put it, "It's easier to dig a hole than to build a pole.")

Despite the demographic overlap, Janet Green of Bodies Like Ours notes that the lesbian community is not always "as supportive of our issue as they possibly could be. In women-born-women-only spaces, it can be an issue, even though girls that have CAH are absolutely girls, women in every sense." In San Francisco's queer community, however, Thea Hillman says that acceptance "is actually pretty widespread. I know several people with intersex conditions. Some present as butch, one has transitioned to male, and one plays with her gender all the time. Each of them has been part of the dyke community."

THE FUTURE OF INTERSEX

This year marks the tenth anniversary of ISNA, and intersex activists have not only mingled with LGBT community figures, they've learned from the strategies of the gay liberation movement. In particular, intersex activists point to the efforts of gay and lesbian activists during the seventies to convince the American Psychiatric Association to remove homosexuality from the list of mental disorders. "They tried to de-medicalize homosexuality and we're trying to de-medicalize intersexuality," says Dreger. ISNA and Bodies Like Ours are also trying to build relationships with other movements, much like the gay community has built bridges to the transgender and women's movements.

Activists are also exploring their options in court. Ideally, Thea Hillman says, there would be "some kind of legal environment where the threat of being sued makes it so doctors can't do these surgeries anymore." (That doesn't mean that the intersex movement advocates against parents picking a sex for the child. As Monica Casper advises, "Based on the evidence you have, pick a sex. But don't do surgery. . . . A parent's distress shouldn't be treated by surgery on their child.")

Luckily, there are a growing number of medical professionals who feel the same way ISNA and Bodies Like Ours do. Many medical students, gay and straight, are questioning the treatment of intersex patients. Hillman warns that for the most part, "the old guard is training the new guard," but some alternative medical protocols are in place. Even researcher Amy Wisniewski of the Johns Hopkins Children's Center, who worked on the 2002 intersex study, acknowledges that "if we ran this study again in fifty years, we hope none of the participants would report a lack of understanding about their condition."

Ending the isolation and misinformation will aid intersex people in coming out and understanding themselves. But society needs to understand intersexuality as well. "Overall, it would be great if society could see that intersex is just a variation, like hair color," Hillman says. "These are healthy functioning bodies; there's no reason to change them just to assuage people's fears." Alice Dreger puts it even more succinctly: "Ideally, we would love it if we became obsolete."

Jen Phillips is the Associate Editor at Girlfriends.

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