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If Biology Is Destiny, When Shouldn't It Be?

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What would you do if your baby was born intersex, with sex organs and external genitalia not clearly male or female? How would you choose whether to bring up your child as a boy or a girl and decide whether doctors should perform corrective genital surgery?

A series of new studies and a book, "Intersex and Identity" (Rutgers University Press, 2003), seek to provide the answers to these questions. Yet despite this research, the ultimate choices may have less to do with a child's medical condition than with the hospital selected for childbirth. If this sounds like an anomaly in an era of evidence-based medicine, you are right.

It was only a dozen years ago that decisions about intersex children, who make up roughly 1 in 2,500 births, were made independently by physicians. So when infants were born with congenital adrenal hyperplasia, in which the female sex organs do not respond to hormones in utero, doctors shortened the enlarged clitorises and created vaginas. Surgeons converted boys born with extremely small penises, a condition known as micropenis, into girls, building clitorises and vaginas.

What led physicians to make such monumental decisions, often without consulting parents? The years after World War II represented a high watermark for Freudian psychiatry, with its emphasis on the significance of external genitalia. Physicians adopted this notion of anatomy as destiny, using surgery to create a clear gender identity.

Postwar surgeons readily removed ovarian or testicular tissue and refashioned external sex organs. As the saying went, "A chance to cut is a chance to cure."

The trouble was, it wasn't clear what was being cured. Or so said a group of intersex people who became activists in the 1990's. Some learned about their histories because of sexual or medical problems involving their genitals. Others obtained their medical records. What united them was anger that their variant genitalia had been treated like a disease and "corrected" secretly.

Foremost among these activists is Cheryl Chase, born in 1957 with a micropenis. Although initially considered to be a boy, doctors eventually amputated her genitals and told her parents to raise her as a girl. She lived with deception and shame for years before going public.

Ms. Chase worked with other intersex people, academicians and doctors to found an advocacy organization, the Intersex Society of North America, in 1993. Like other health related advocacy groups that emerged after 1970, the society promoted full disclosure of medical information and informed consent. In the case of intersex, this strategy meant making parents active partners in decisions.

Dr. Alice D. Dreger, a historian of medicine who until recently was the chairwoman of the intersex society's board, says that surgeons had sought to convert complex psychosocial issues into simple anatomical problems that could be fixed. This strategy, she adds, is based on supposition, not research.

Given that such claims challenged long accepted dogma, it is not surprising that many surgeons and endocrinologists responded defensively. Some called the activists zealots.

Today, almost all doctors involved with intersex infants say they believe that parents must actively participate in decisions. But that is where agreement ends.

The intersex society has recently called for a moratorium on all nonlifesaving surgery on intersex children until they are old enough to participate in decisions. This policy stems in part from several recent studies, which found sexual and psychological problems among intersex adults who had surgery as infants.

In one study, published in *The Lancet* in April, Catherine L. Minto, a British researcher, surveyed 39 intersex adults who were reared as women. All 28 who were sexually active reported having sexual difficulties; 18 who had undergone clitoral surgery said they had often experienced inability to achieve orgasm. Sharon E. Preves, a sociologist at Hamline University in Minnesota, who interviewed 37 intersex adults for "Intersex and Identity," agrees, adding that the surgery is "experienced as degrading and shaming."

"I have yet to read about, hear or meet an intersex person who is grateful for surgery done on them as an infant," said Dr. Monica J. Casper, a sociologist who is executive director of the intersex society.

When certain physicians, like Philip Gruppuso, a pediatric endocrinologist at Brown, see an intersex infant, they now usually recommend against surgery. Lacking proof of its value, Dr. Gruppuso says, deferring surgery is easy.

Other doctors, however, object to such a blanket policy. It is one thing to advocate for patient autonomy, Dr. Kenneth I. Glassberg, a pediatric urologist at Columbia University, wrote in *The Journal of Urology*, but quite another to allow children with variant genitalia to "be considered freaks by their classmates."

While Dr. Glassberg acknowledges that some celebrated cases of corrective surgery have gone poorly, he adds that most patients — akin to a silent majority — are content with their outcomes. A hard-and-fast rule against early surgery, he says, "is itself experimental, and more of an experiment" than the operations.

One possible solution lies in collecting more data. A new task force, led by by a Medical University of South Carolina pediatric urologist, Dr. Ian A. Aaronson, is to issue formal guidelines.

Yet gathering such information and applying it to the lives of newborns will not be easy. For one thing, most of the survey data come from intersex people who belong to activist groups. While compelling, these interviews may represent a biased sample.

An intersex condition is not pneumonia, a medical problem amenable to antibiotics and outcome studies. Given the wide variety of intersex conditions and the intensely personal issues they raise, not even better data will provide parents with easy answers.