



By Kate Scannell, MD, Editor
Commentary by Anne Fausto-Sterling, PhD

Engendering Differences: Ethical Issues about Intersex

In 1993, biologist Dr Anne Fausto-Sterling published in the journal *The Sciences* a provocative and somewhat tongue-in-cheek essay, “The Five Sexes,” that challenged the traditional dichotomous model of human sex and sexuality. In addition to the existence of females and males, she proposed that there existed “herms” (named after true hermaphrodites, who have both a testis and an ovary), “ferms” (female pseudohermaphrodites—people born with ovaries and some expression of male genitalia), and “merms” (male pseudohermaphrodites, people with testes and some expression of female genitalia). In addition, she calculated that about 1.7% of all births were, in some form, intersexual (ie, characterized by various interminglings of male and female sex characteristics) and that genital surgery was performed on approximately 2000 children in the US each year.

Dr Fausto-Sterling’s challenge to the traditional binary sex and gender system stimulated extensive controversy and disturbed entrenched medical values and social norms. Besides forcing the issue of intersex into medical and public discussion, she also recommended a radical reconceptualization of the way the medical establishment should and could treat intersexed children. The customary approach had been surgical since the 1970s: operative removal of gonads and genitalia attributed to one of the two traditional sexes; and surgical and hormonal enhancement of those attributed to the opposite sex. Usually, the choice of sexual phenotype promotion was made according to the appearance of the child’s extant genitalia. At a minimum, it was thought that a boy should have a penis at least one inch long in stretched length at birth, and a girl should not have a clitoris longer than 3/8 inch. Body “normalizing” also generally included as-needed surgical provision of a vagina suitable for future intercourse for girls, and, for boys, a urethral opening at the tip of the penis.

During recent years, segments of the medical and intersex communities have questioned the practice of surgical genitoplasties and sexual assignment of intersexed infants. Modern-day medical opinion is now divided. The American Academy of Pediatrics’ 2000 guidelines for evaluation and management of intersex infants with “ambiguous genitalia” call for early surgery in selected cases; they also include the following statement: “Although newborns with ambiguous genitalia are encountered rarely in a pri-

mary care pediatrician’s practice, their diagnosis and prompt treatment require urgent medical attention.”

But challenges to conventional surgical approaches and views of intersexed conditions as “medical emergencies” have arisen largely because of the increasing visibility of intersex persons who have reached adulthood and who offer us their experiences. These experiences are critical in that they are told by subjects of surgical procedures that are performed as standard practice despite the absence of scientific data supporting benefits. To this date, there exist no comprehensive, retrospective studies that establish a therapeutic benefit from surgery.

What we are learning anew from the intersex community is that sexual and gender identifications are more complex than any surgical decision that purports to divide human experience of it into two neat classifications. Indeed, many intersex children later suffer their surgical assignment because of strong identification with the “excised” sex or lessened sexual sensitivity of their modified organs. Thus, there is cause to consider a moratorium on surgical interventions performed on intersex infants until some evidence supports its benefit.

Seven years after the appearance of her essay, Dr Fausto-Sterling published “The Five Sexes—Revisited” in the same journal. In this revisitation, she noted that since 1993, “modern society has moved beyond five sexes to the recognition that gender variation is normal.” She also acceded to a view of gender attribution that gave less signifying power to genital makeup and more weight to both gender performance and self-determination of sexual and gender identity. She proposed: “It might seem natural to regard intersexual and transgendered people as living midway between the poles of male and female. But male and female, masculine and feminine cannot be parsed as some kind of continuum. Rather, sex and gender are best conceptualized as points in a multi-dimensional space.”

As intersexed people clearly demonstrate, strict sexual dimorphism does not exist in nature. And as human nature does not abide by cultural rules, rigid and anatomically based conceptualizations of gender identity do not suffice to account for the authentic experiences of human beings being human.

It is a simple truth that intersex children are born, and this fact can serve as an elegant reminder about

[Biologist Anne Fausto-Sterling argues that] “sex and gender are best conceptualized as points in a multi-dimensional space.”

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the diversity of sex and the human body at a cellular level. At a cultural level, we have been learning much about the wide spectrum of sexual and gender identities that defy binary classification systems. And we have witnessed the changing and fluid "boundaries" imperfectly separating male and female societal roles as well as feminine and masculine traits and behaviors. Recognizing the myriad ways that human lives are born into the world in all their various shapes and sizes, sexes, and degrees of health may reflect and foster a respectful acceptance of humanity at the level of "what is."

**Case Study:
When an Intersex Child is Born**

Ira and Karen were shocked when doctors informed them that their newborn child, Jamie, was a hermaphrodite. The doctors offered to perform "sexual assignment surgery" for Jamie's "correctable deformity" in order to protect the child and parents from any sense of ambiguity. They summarized Jamie's "ambiguous genitalia" as one undescended testicle; a phallus longer than a clitoris but lacking the definitive features of a penis; an absent vaginal opening; and a rudimentary intra-abdominal ovary and uterus. They explained that they surgically assigned most intersexed babies as female because the surgical techniques were more successful, and they could not create a functioning penis. Female hormones and surgical construction of a vagina could be delayed until Jamie was sexually active.

Ira and Karen brought Jamie home and argued about the decision. Ira insisted that the surgery be performed so Jamie could experience a "basic human need for a sexual identity." Karen disagreed, echoing advice she received from both a psycholo-

gist and a counselor at an intersex support agency. She said that Jamie could be raised with a regular gender identity without genital reconstruction but with a sex-stereotypical name and clothing. She insisted that Jamie should decide whether to have sexual assignment surgery upon reaching adulthood.

At medical follow-up, the pediatrician and urologist informed Ira and Karen that Jamie's intersexuality was caused by chromosomal mosaicism—an XY/XO pattern. They recommended removing Jamie's intra-abdominal gonad and undescended testicle to reduce cancer risks, minimize and move the enlarged urethral opening to make space for future vaginal construction, create labia from foreskin and scrotal skin, and perform clitoroplasty by reducing Jamie's phallus to the size of a clitoris. They were concerned that, without imminent surgery, hormonal exposure would further masculinize the brain, gender-imprinting Jamie, and thus result in a male identity.

When doctors inquired whether a decision had been reached on sexual assignment surgery, Ira broke down and voiced his fears that, without surgery, Jamie would face constant derision and alienation, embarrassment in the locker room, and hesitation initiating a sexual life in adulthood. But Karen was just as fearful that a clitoroplasty would diminish Jamie's future sexual sensitivity and that if Jamie were already gender-imprinted to identify as male, the proposed surgery would leave Jamie sexually damaged.

- What should Jamie's parents do?*
- What ethical principles are raised in this case?*
- Is sexual assignment surgery cosmetic or medical?*
- What are the doctors' obligations to Jamie?*
- Whose opinion prevails when the parents disagree about medical procedures for their children? ♦*

Case Commentary

Anne Fausto-Sterling, PhD, Brown University Medical School

In making management decisions about a complex case of intersexuality, the first step should be a frank admission of uncertainty. Even the basic facts of the matter here are unclear. Is the gonad an ovary, as suggested at first, or a testicle? Is either of the gonads making hormones, which might be especially important for subsequent growth and bone development? How much of the body is mosaic? Will puberty be masculinizing or feminizing? And, most important of all, what will the child's gender identity be

as he/she reaches conscious expression in the first decade of life? Neither the doctors nor the parents have reliable answers to any of these questions, no matter what they claim. Thus, I think the most conservative approach should be taken—don't cut out anything that you may later decide you wish the patient still had.

But what are the medical and emotional concerns? The cancer question is the easiest: In these cases, an increased risk of cancer emerges after puberty, so



there is no need to remove the gonads earlier. Furthermore, either a functional testis or ovary can aid bone development, reducing the risk of osteoporosis that results from gonadectomy. If the testis is functional and if Jamie adopts a male gender identity, it might even be possible to use spermatogonial nuclei for in vitro fertilization—thus permitting the possibility of fatherhood later in life. If the testis does not make its own hormones but the child develops a male gender identity, then leaving the phallus intact will give the pediatric endocrinologist the possibility of using exogenous testosterone to induce growth.

What of Ira’s fears about life in the locker room? With proper and practical counseling, the anticipated teasing can be minimized or avoided. Parents can arrange for their children to have privacy while dressing and undressing in schools. There is nothing visibly odd about such children as long as they are wearing clothes. Proper counseling can also help family

members talk with each other, developing an atmosphere in which sexual development can be explained to the child and in which all matters relating to Jamie’s development can be openly discussed.

Finally, Karen is concerned that gender imprinting might have already occurred and that surgery could leave Jamie without the requisite parts needed to carry out that imprinting. Karen could be right, and that is the point. We don’t really know how gender identity develops, but we do know that mistakes in gender assignment occur—ie, the doctors’ “best guess” about future gender identity sometimes turns out to be wrong. Again, this fact strongly suggests that the best course is to postpone surgery and provide maximum counseling to the family—including advice about how to protect Jamie from teasing by his/her peers. Close observation and discussions with Jamie should enable some clarity about gender identity within the first five years, and the child’s voice should be heard. ❖

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Physical Concepts

Physical concepts are free creations of the human mind, and are not, however it may seem, uniquely determined by the external world.

Albert Einstein, 1879-1955, Winner of the Nobel Prize in Physics, 1921