Fixing Sex: Intersex, Medical Authority, and Lived Experience

Author: Katrina Karkazis
384 pp., $23.95 paperback

Generally, the diagnosis of sex at birth is quite superficial; anyone looking at the external genitalia of a newborn may declare “it is a girl” or “it is a boy,” because such observations are quite obvious at first glance. Pediatric Endocrinologists and other medical professionals will have to deal with infants whose external genitalia are not quite masculine or feminine. They will also have to face a family in disarray: a tired mother recovering from delivery, an anxious father, siblings, grandparents, coworkers, and neighbors, all of whom will want to know whether the baby is a girl or a boy.

This is where “Fixing Sex,” a book by Katrina Karkazis, brings us. Dr. Karkazis is a Senior Research Scholar with the Center for Biomedical Ethics of Stanford Medical School. She is said to be “a cultural anthropologist with a particular interest in contemporary biomedicine,” and she is part of the Advisory Committee of “Accord Alliance,” a new intersex support group.

The introduction of the book underlines a movement in the early 1990s, during which a group of intersex activists loudly brought their problems to the attention of the medical community and the world. For this group, early genital surgery was particularly emphasized as “wrong, and a torture...” because “intersex people are not sick, they are not in need of care, but so-called rational medicine is coming after those kids with knives in their hands.” Adding to the movement was the perceived incredible spin put on one sad case of “ablatio-penis.”

Part 1 of the book resumes the history of intersexuality, stating that in the early 20th century, there was an increased awareness of sexual ambiguity. Highlighted is the Young and Davis book Practice of Urology, in which early surgical techniques were described as the correction of “hermaphroditic patients.”

Karkazis reports that the next important step, in the 1950s, is the work of John Money, with Lawson Wilkins, J.G. and J.L. Hampson, and Anke Ehrhardt. This section states that Money presented a “nuanced analysis of the complexity of biological sex.” These researchers introduced the terms “gender,” “gender role,” and “gender identity.” They also underlined “the role of rearing and socialization in shaping gender role.” Recognizing the importance of nature and nurture in sexuality, they concluded that nurture would eventually tend to dominate.

The author then describes the challenge brought up by Milton Diamond who, on the basis of his animal experiments, concluded that nurture was the primordial influence, “gender being determined by biology.” The author shows clearly that the subtle difference between Diamond and Money was that for Diamond, prenatal androgens determined male gender, but for Money, they had only an influence on gender role but not on gender identity. The “John/Joan” case, as described by Colapinto in his book As Nature Made Him: The Boy Was Raised As A Girl, is shown as the media, with little scientific backup, playing a major role in the views of the general public.

In Part 2, the author reviews the methods used for sex assignment in intersex infants. The “sexing of the brain,” the “genitals as signifiers,” the “diminishing importance of penis size,” the “power of chromosomes,” problems related to fertility, the extent of required surgery, and parental wishes: all of these factors and their numerous individual variations can lead to the conclusion that there is no correct response to this issue.

In this Part 2, there is also a discussion of “Early Genital Surgery.” This is a most important subject, because it remains a major point of contention among physicians and activist groups.

Part 3 considers the question of the actual sex assignment of newborns with ambiguous external genitalia. In this section, Dr. Karkazis interviewed the parents of infants presenting with either complete androgen insensitivity syndrome (CAIS) or congenital adrenal hyperplasia. This choice of disorders is probably inappropriate, given that these two groups make up the less problematic patients as far as decision about sex assignment is concerned.

The last fifty pages of the book report on the history of activism related to intersex, particularly the activities of the Intersex Society of North America (ISNA).

The conclusion is quite fitting, noting that “the history of thinking about the body demonstrates that its functions, specific organs, and other attributes can be highly politicized and controversial.” Karkazis does a good job of presenting these controversies.

In summary, this book would be an interesting read for all involved in the study of disorders of sexual development (DSD), including pediatricians, geneticists, gynecologists, and urologists.

Claude J. Migeon1,*
1Department of Pediatrics, Johns Hopkins University, Baltimore, MD 21287, USA

*Correspondence: cmigeon@jhm.edu
DOI 10.1016/j.ajhg.2009.04.022. ©2009 by The American Society of Human Genetics. All rights reserved.