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Fixing Sex: Intersex, Medical Authority, And Lived Experience



Synopsis

What happens when a baby is born with “ambiguous” genitalia or a combination of “male” and “female” body parts? Clinicians and parents in these situations are confronted with complicated questions such as whether a girl can have XY chromosomes, or whether some penises are “too small” for a male sex assignment. Since the 1950s, standard treatment has involved determining a sex for these infants and performing surgery to normalize the infant’s genitalia. Over the past decade intersex advocates have mounted unprecedented challenges to treatment, offering alternative perspectives about the meaning and appropriate medical response to intersexuality and driving the field of those who treat intersex conditions into a deep crisis. Katrina Karkazis offers a nuanced, compassionate picture of these charged issues in *Fixing Sex*, the first book to examine contemporary controversies over the medical management of intersexuality in the United States from the multiple perspectives of those most intimately involved. Drawing extensively on interviews with adults with intersex conditions, parents, and physicians, Karkazis moves beyond the heated rhetoric to reveal the complex reality of how intersexuality is understood, treated, and experienced today. As she unravels the historical, technological, social, and political forces that have culminated in debates surrounding intersexuality, Karkazis exposes the contentious disagreements among theorists, physicians, intersex adults, activists, and parents—and all that those debates imply about gender and the changing landscape of intersex management. She argues that by viewing intersexuality exclusively through a narrow medical lens we avoid much more difficult questions. Do gender atypical bodies require treatment? Should physicians intervene to control the “sex” of the body? As this illuminating book reveals, debates over treatment for intersexuality force reassessment of the seemingly natural connections between gender, biology, and the body.

Book Information

Paperback: 384 pages

Publisher: Duke University Press Books; 1 edition (November 14, 2008)

Language: English

ISBN-10: 0822343185

ISBN-13: 978-0822343189

Product Dimensions: 6.1 x 1 x 9.2 inches

Shipping Weight: 1.2 pounds (View shipping rates and policies)

Average Customer Review: 4.4 out of 5 stars 9 customer reviews

Best Sellers Rank: #271,101 in Books (See Top 100 in Books) #22 in [Books > Textbooks > Medicine & Health Sciences > Medicine > Clinical > Surgery > Urology](#) #36 in [Books > Medical Books > Medicine > Internal Medicine > Urology](#) #41 in [Books > Textbooks > Medicine & Health Sciences > Medicine > Clinical > Endocrinology](#)

Customer Reviews

"Fixing Sex is the best book I have ever read over the years which deals with the ethical issues which have plagued the intersex community, parents and doctors. One reason is that it is meticulously researched and in the introduction, the author helps the reader understand her methodology and also makes it transparent and easy to grasp for the reader who is not familiar with such research. . . . Katrina Karkazis has written a book that both I (an intersex activist) and a medical doctor can read and understand and not be upset about. Now that is a tour de force."

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My only wish is that there could be a translation of this book to as many languages as possible. It has a very broad angle, and I thank the author for covering as many points of view as she could, while exercising an objectivity when focusing on medical protocols. To a lay person like me, who indeed held hard feelings towards the medical community for my personal case, and almost demonized John Money's work and life, this book was an eye-opener on how hard it is not just for them as practitioners, specialists and researchers but as human beings, framed within a society where there are unquestioned principles and uncontested claims on gender issues that intersex condition challenges. This leaves the reader with the mission of uniting the struggle to create consciousness about gender and sex not being binary nor determined by the traditional biological markers. My only wish, apart from it being translated to spanish (I know a lot of people who could gain great insight and orientation but who are unable to read it because they're not bilingual), would be for the author to spread her observations and conclusions to a broader audience, since this topic

is hardly exclusive to American cases (she acknowledges, for instance, the legal fight of a Colombian intersex teen). But that, maybe, is a task for each one of us.

Let me first note that I'm an intersex person who tends to read whatever I can find on the topic. Over the past decade, there has been a modest burst of publishing on intersex status (or what the medical field now terms "DSDs" for "Disorders of Sex Development"), but much of what books cover overlaps. Books tend to fall into one of two categories. There are those with a hard science perspective, which take an "expert" standpoint to explain why people are born intersexed and what that shows us about prenatal development, evolution, the role of hormones, etc. Then there are those with an advocacy perspective, that point out that the current medical "treatment" for children born intersex--infant surgical sex assignment--is highly problematic, because it often leads to the sacrifice of sexual sensation, and because the sex assigned at birth can be the wrong one. What Karkazis does in her book is to bridge the gap between a focus on science and a focus on the experiences of intersex people. She interviews doctors, parents of intersex children, and adult intersex individuals to lay out for the reader their various perspectives. Her basic conclusion is that medical practitioners are ignorant of or dismiss the experiences of intersex adults, which leads doctors to continue to advocate and perform infant sex assignment procedures despite the manifestly negative consequences for many intersex people. She also shows how doctors' stance--that intersex status is a defect, a social emergency that can and must be treated medically--convinces parents to consent to treatments that they often later regret condoning. So Karkazis' findings are in line with books written by intersex advocates. But by including medical information and interviews with medical practitioners, Karkazis shows her readers why the unhappiness of intersex people with treatment they receive has not done much to change medical practice.

Katrina Karkazis' *Fixing Sex* is an ambitious attempt to deal with the multiple issues brought up by those born with Intersex Conditions (I'm going to use that term over DSDs) their parents and the doctors who 'treated' them. She comes clearly down on the side against performing 'normalising' procedures on infants often by performing surgery on larger than average clitorises (in some cases, performing actual clitorodectomies) or reassigning xy children with micropenises as female. She points out how doctors are slowly reevaluating how these procedures are done (or whether they're done) but are still highly defensive about the medical decisions they're made and, especially, about the harm they've caused. For those following the Intersex community and their often heartbreaking

stories, the book can be painful to read. But Ms. Karkazis tries to present the material not as an advocate, but as a medical ethicist and she succeeds brilliantly in shining much light on a lot of dark histories than are still threatening to all involved. It's in dealing with these bioethical questions the book finds its greatest success. She balances the choices parents and doctors made for infants with the anger and helplessness of those children who had to actually live with those decisions. She also points out how adherence to 'normality' and the gender binary had everything to do with many of these (often for the worse) life-altering decisions. There are some parts of the discussion I wished the book had keyed into with more detail and first person narratives. She talks to almost no one who was gender reassigned, either those still living in their assigned gender nor those who were uncomfortable in their assigned gender and later transitioned back. I feel she shortchanges some of the connections between the Intersex and Trans communities, which includes a goodly number of people born with Intersex conditions. Perhaps it's Karkazis seeming connections to Bo Laurent (formerly Cheryl Chase) and Alice Dreger that kept her from discussing this important linkage between the two communities. I was also disturbed that Karkazis, in a discussion of David Reimer and gender identity, makes a fairly sweeping conclusion about in utero hormonal exposure, and CAH (and I don't think anyone would say exposure to hormones is the same for anyone, there are many biological and experiential factors that can alter the outcome) that I found myself shaking my head while reading. Likewise, she makes a statement that David Reimer was one case, but there was another similar non-Intersex reassignment case where the reassignment worked and that, somehow modifies the conclusions of Milton Diamond and William Reiner and others. However, she gives information in her endnotes that suggests this reassignment might not have worked quite as well as how she referenced it in the main body of her text. It was a little sloppy. Still, anyone interested in Intersex, bioethics, gender and just the intense human drama that surrounds how we 'normalize' sex and gender owes it to themselves to read *Fixing Sex*. The many anonymous quotes in the book and still-raging debates between defensive medical practitioners, angry Intersex adults, guilt-ridden parents and dueling support organizations show how painful an issue this is, and Karkazis has done a wonderful navigating through it.

In this highly detailed and thorough work, Katrina does an excellent job flushing out what has occurred over the past few decades to lead to today's viewpoints on disorders of sex differentiation (intersex). We seriously need to rethink our approach to any genital surgery on children, and her book offers great potential for us to see the forest and step out of our current box!

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