

Ellen K. Feder

*Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine*

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During the past two decades, both activists and researchers have subjected to critical scrutiny the standard of care for children born with atypical sex anatomy. People with intersex conditions--who as children were subjected to normalizing surgeries and/or sex reassignment and then were not told about these interventions--have testified to the violations and sometimes irreparable harm of medical care. However, in spite of serious and well-founded criticism, as well as changes in regulations, medical practice remains to a great extent unchanged, and normalization, mainly through surgical intervention, of the bodies of children with intersex conditions as soon as possible after birth is still commonly considered to be the best option for managing cases of ambiguous sex. The question of why the by-now rather widely recognized understanding of the ethical violence involved in medical interventions has not made the standard of care obsolete is at the center of Ellen K. Feder's thorough and compassionate study *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine*.

The book, Feder writes in the introduction, is the result of a fifteen-year-long project of thinking through what philosophy might be able to offer to critical thinking about the medical management of intersex. Seeking to answer this question, Feder gives her readers much more than a thorough and sophisticated philosophical analysis as she moves beyond philosophy and engages also the history of medicine, policy documents, and medical texts, as well as conducts interviews with individuals with intersex conditions, parents of children with intersex, and doctors who perform normalizing surgeries. The book furthermore contains the first account of the experience of a sibling of a person born with atypical sex anatomy who was subjected to normalizing surgery.

Feder begins her study, following the introduction, with a historical overview of changing perspectives on "the problem" of intersex and of the development of the standard of care crafted in the 1950s that medicalized atypical sex anatomies and "sought to make individuals' sex of assignment consistent with their body's appearance" (14). Tracing the history of intersex, she identifies a "cyclic movement" whereby atypical sex anatomies in different ways have been constituted as a threat,

first to the social order, then to individual well-being and finally back again to society. Parallel to this cyclic movement runs a process of medicalization transforming the social threat of atypical sex into an object for medicine, taking on the task of removing the threat through normalizing surgery. Feder emphasizes that the conceptualization of intersex is not simply a process of pathologization of something unusual. Instead, at the time when the standard of care was crafted, atypical sex anatomies were considered alternately and simultaneously to be anomalous or merely unusual and to be pathological in the sense that they interrupted a normal life course. The dual constitution of intersex conditions as both a social and medical danger is, argues Feder, what made them "extraordinary" cases, or "disorders like no other" and what has come to justify "the routine violations of well-established ethical principles through the end of the twentieth century" (15).

Bringing to light the complexities in the history of intersex, Feder shows that the medicalization of atypical sex anatomies is not always only about medicalizing conditions that might be better understood in social or psychological terms but also, and importantly, about recognizing that some conditions with which atypical sex is associated, such as congenital adrenal hyperplasia (CAH), need medical attention beyond that concerned with normalizing genital appearance. However, as the standard of care was crafted, focus was directed at atypical genitalia as that which needed medical treatment, and cosmetic normalizing surgery was seen as a necessary part of the medical management of CAH. Although this view, as Feder writes, has shifted significantly and decisions to perform normalizing surgeries in cases of CAH are now seen as distinct from decisions regarding other aspects of care, atypical genitalia nevertheless still figure as a threat to a social order considered as natural, and normalizing surgery is seen as a way of correcting an error of nature.

The historical overview Feder sketches of how the standard of care for intersex conditions developed brings out the motivating force behind surgical intervention to be an unquestioned imperative of normality and a determination to do away with what is perceived as a social danger. In the following chapters she examines how this imperative and desire for normality is articulated and enforced in different ways, by parents and doctors as well as by individuals with intersex conditions.

Chapter 2 tells the stories of some parents of children with intersex conditions in light of an analysis of Pierre Bourdieu's notion of *habitus*, which designates an unquestioned or taken for granted realm of common sense. The habitus of binary sexual difference both governs and is governed by normalizing practices that are seen as being carried out in the best interest of the child born with atypical sex anatomy. The Bourdieuan framework also enables Feder to address the paradoxical results of a paired study where a majority of participants responded that had they been born with an intersex condition, they would not have wanted their parents to agree to normalizing surgery on their behalf, but when asked to imagine themselves as parents of a child with ambiguous sex anatomy, the majority state that they would consent to such surgical intervention on behalf of their child. The notion of *habitus*, which Feder describes as an implicit normative order, captures how conventions not only of normality and of gender, but also of good parenting, work through individuals rather than being reflected upon and thoughtfully enacted by individuals. She suggests that rather than being concerned with how bodies appear, we should imaginatively consider the somatic experience of children through our own bodily self-experience.

The desire for and imperative of normality is brought out throughout Feder's book from first-person perspectives through the stories of individuals with intersex conditions. One of the stories Feder recounts is that of Andie, who was identified at birth as a girl with CAH and who went through normalizing surgery as a child (chapter 5). Andie's story is told as one of the desire not to be different, to be a normal girl like any other girl, which also meant not desiring other girls. Feder notes the close connection in Andie's story between the perception of sexual anatomy and sexual desire, and points to the threat of homosexual desire as one of the reasons "that normalizing surgery was, and perhaps continues to be, recommended" (115). Here, in the discussion of the case of Andie and her desire to be and feel like a normal girl, it would have been valuable to have some further reflection on the heteronormativity of binary sexual difference and on how, within a heteronormative framework, the very terms of being a woman (or a man) includes a requirement of heterosexual desire. This is something Feder discusses, for instance, in her historical overview detailing the changing perspectives on intersex conditions, but by so clearly illustrating the lived experience of the requirement of heterosexual desire in the constitution of gender and sexed bodies, Andie's case invites additional reflection on the connection between sexual anatomy and sexual desire. Feder's claim that the threat of homosexuality has played and perhaps continues to play a role in the recommendations for normalizing surgery mirrors Judith Butler's claim in *Gender Trouble* that the idea of an interior gender core, a natural sex, or real women and men, is "maintained for the purposes of the regulation of sexuality within the obligatory frame of reproductive heterosexuality" (Butler 1990, 136). Further, Butler famously argues that not only binary sexual difference but also *desire* is produced within this frame and governed by a "heterosexual matrix . . . through which bodies, genders and desires are naturalized" (151, note 6). The story of Andie illustrates Butler's point about the interconnection of the production of natural bodies, genders, and desires. Although the normalizing surgery to which Andie was subjected may well have been motivated, at least in part, by a desire to reinforce reproductive heterosexuality and do away with the threat of lesbianism, Andie's own discipline to reject her lesbian desires is described as propelled by a realization that within a heteronormative framework, no amount of normalizing surgery would make her a normal girl as long as her body harbored lesbian desires.

One of the most interesting discussions in the book is that of the idea of "enviable ambiguity" as underlying the imperative of normality (chapter 3). Drawing on Nietzsche's genealogy of morality, Feder suggests a shift of focus from the bodies with atypical sex anatomies to the bodies of those whose responses are what motivate normalizing interventions. The concealment of atypical sex anatomies that surgical and pharmaceutical interventions seeks to achieve makes the bodies of persons with atypical sex into a fixable problem, a nature's error that medicine can correct. In contrast to such a view, Feder proposes that we locate the problem "with those who find intolerable the variation that those with atypical sex anatomies embody" (3) and who provoke shame and self-hatred through their intolerance. She asks the somewhat provocative question of what it would mean if it turns out that the medical management of intersex or disorders of sexual development has been significantly influenced by feelings of disgust, primarily disgust of doctors--whose expressions she cites--but also disgust promoted by doctors in parents of children born with intersex conditions, and she suggests an understanding of this disgust "as a contemporary

expression of what Nietzsche called '*ressentiment*'" (67). *Ressentiment* in Nietzsche's genealogy of morality is a cocktail of feelings of hate, powerlessness, and envy of the powerful nobles that leads to a slave revolt and the birth of morality through what he calls a transvaluation of all values. Feder highlights envy as the origin of *ressentiment* in Nietzsche's genealogy of morality and turns to Max Scheler's discussion of the envy of *ressentiment* in terms of a repressed or impotent envy that has no genuine desire for a given quality, but is instead transformed into hatred against individuals associated with this quality, escalating to the point of falsely considering them the cause of one's privation. Bringing together Scheler's analysis of the impotent envy of *ressentiment* with Freud's account of the losses involved in the assumption of binary gender roles, Feder makes a compelling case for the role of envy in the medical management of intersex and in the creation of the standard of care. Acknowledging a repressed, impotent envy of *ressentiment* as an important part of what motivates normalizing surgical intervention in cases of children with intersex conditions can help explain, argues Feder, how the care for individual children can allow for the risk and harm involved in these procedures.

In order to better understand the harm brought about by normalizing interventions of atypical sex anatomies and the violations such interventions entail, Feder turns to Merleau-Ponty's notion of the body schema (chapter 4). Bridging the "physical" and the "psychological," Merleau-Ponty's understanding of embodied subjectivity offers a fruitful way of approaching and conceptualizing the harms involved in the medical management of intersex, as harms to one's sense of self and to the totality of one's being. Merleau-Ponty's account of the constitutive interrelation between the embodied self, others, and a shared world further points toward an exploration of an embodied ethics and of a view of parenting as an embodied practice of transformation, which Feder develops in the final chapters of the book.

To ground an ethics for the medical care of persons born with atypical sex anatomy (and an ethics more generally), Feder turns attention to the notion of a shared human corporeal vulnerability. Rather than a traditional focus on the supposed vulnerability of the child, she highlights how a shared corporeal vulnerability is articulated in parents and medical professionals. Drawing on Debra Bergoffen's recent work on the vulnerability of the body and our ethical obligation to honor the dignity of the vulnerable body, Feder puts forth the idea that parents, instead of aiming to protect against their children's vulnerability, have an obligation to affirm it and by so doing also affirm their own vulnerability. With her account of the ethical value of vulnerability, she joins recent theories of vulnerability as a condition of life and an essential aspect of human existence, rejecting a common conceptualization of vulnerability as something negative, in terms of a weakness to be overcome. *Making Sense of Intersex* offers ample evidence of the harm of protecting against a certain vulnerability, and Feder convincingly argues against attempting to overcome vulnerability through invasive procedures of normalization. However, the book also brings to mind Butler's observation that vulnerability "cannot be properly thought of outside a differentiated field of power and, specifically, the differential operation of norms of recognition" (Butler 2004, 44), and it raises questions about how affirming vulnerability can and should be done. What are the risks involved in affirming vulnerability? On whose conditions is such vulnerability affirmed and from whose perspective is the common and the shared understood? How is vulnerability articulated in different ways and also affirmed and protected in different ways? These

are questions that Feder does not address at any length but to which her study quite urgently gives rise.

*Making Sense of Intersex* is an impressive work that makes a significant contribution not only to furthering our understanding of intersex and the ethical issues involved in the medical management of atypical sex anatomy but also more generally to both feminist philosophy and ethics. The book importantly notes multiple and diverse ways of being sexed and thereby offers new ways of making sense of intersex that do not reduce intersex conditions to mistakes that can and should be fixed through medical intervention. Feder furthermore raises important questions about processes of medicalization, the force of normative structures, the constitution and creation of normality, and how we act on behalf of others, guided by what we think are in their best interests, that go beyond the medical management of atypical sex anatomies. Her book invites its readers to continuously raise new questions and forge new encounters across disciplines concerning such questions.

#### References

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