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Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine
by Ellen Feder (review)

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Review: Ellen Feder, *Making Sense of Intersex: Changing Ethical Perspectives in Biomedicine*, Indiana University Press, 2014

In the 21st century, why is the birth of a child with atypical sex still considered a social emergency? Moreover, why does this social emergency continue to be treated as a medical problem? Given the powerful testimony of intersex scholars and activists over the past several decades about the significant harms perpetrated by the standard medical treatments, including genital surgery on infants, what accounts for the persistence of these practices?

Ellen Feder's important and impressively researched book, *Making Sense of Intersex*, makes a substantial contribution to these questions. By wading into the discussion on intersex treatment, Feder is well aware that she is entering a strange combination of well-worn territory and stubborn silences. Citing a litany of feminist theorists who have deployed intersex as a powerful example of the social construction of biological sex, Feder establishes early in the text that she seeks to recast the problem "not as one concerned with gender and genitalia, but as an *ethical* problem—that is to say, a problem located with those who find intolerable the variation that those with atypical sex anatomies embody" (2-3, emphasis added). By foregrounding ethics, in other words, Feder seeks to avoid a single-minded focus on sexual difference that she believes has dominated the conversation

for too long. She takes inspiration on this front from a number of scholars and activists, such as Cheryl Chase and Suzanne Kessler, who have worked to resituate the “problem” of intersex as one of “stigma and trauma, not gender” (Chase quoted in Feder, 66).

As Feder develops her argument that the treatment of intersex should be understood as an ethical problem, she expects that the field of bioethics will be an obvious resource. To the contrary, however—and as detailed in a short history of bioethics in the opening pages of this book—she was surprised by the silence on the subject not only from philosophers in general but also from bioethicists in particular. Linking this silence to the ‘confinement’ of philosophy in the wake of the McCarthy era detailed by John McCumber in *Time in the Ditch*, Feder articulates both the promise of bioethics—as an applied field of philosophy that tackles concrete problems—and the limits of bioethics, limits that become especially apparent when bioethicists cast their primary aim as that of serving medical practitioners, or as “providing answers to questions that they [philosophers] are not permitted to pose themselves” (9).

In working to reinvigorate the philosophical creativity of bioethics, Feder argues that we should face the failures of conventional ethical frameworks (e.g. rights, autonomy, informed consent, enumeration of harms) to account for the prevailing models of decision-making and avail ourselves of different tools. In developing this toolbox, *Making Sense of Intersex* is distinctive (in the bioethics literature on medical issues and in the feminist literature on intersex) for at least three reasons. First, Feder draws on philosophy from the continental tradition. Many of these thinkers, such as Pierre Bourdieu (chapter 2), Friedrich Nietzsche and Sigmund Freud (chapter 3), and Maurice Merleau-Ponty (chapter 4), are not often present in discussions of medical ethics. Second, while *Making Sense of Intersex* is clearly indebted to the critiques of the medicalization put forward by intersex and feminist scholars and activists, Feder complicates a purely social reading of intersex conditions throughout the text. While she acknowledges that “the case [for demedicalization] is undeniably convincing [...] there is an equally compelling case that some of the conditions with which genital variation are associated bring genuine health challenges that require not less, but substantially more, medical attention than has been afforded them” (21). Finally, her work relies on empirical research. “Talking to people had played no significant role in my training in philosophy” (11), Feder amusingly writes, and yet the lack of academic engagement with many of the topics driving her interest—such

as the relationships between children, parents, and physicians, as well as the changing standard of care—led her to seek out conversations with parents and physicians that might fill some of these gaps.

Throughout *Making Sense of Intersex*, Feder argues that medical practitioners and bioethicists can both hold on to their fundamental concern to “think practically” (16) (a concern Feder shares) and do far more to examine the role of relationships, affect, and power in the management of intersex conditions. The “history lessons” of the first chapter nicely set the stage for this shift in perspective. While one dominant narrative portrays the history of intersex as a march from social curiosity to medicalized treatment, Feder argues that the treatment protocols developed in the early 20th century actually revitalize this earlier fascination with the potential social danger of intersex, producing a “convergence” that makes a number of related conditions become “disorders like no other” (15). Using Michel Foucault’s account of normalization, the second part of the chapter examines both the ongoing medicalization of this social anxiety and the emergence of a counter-movement at the end of the 20th and beginning of the 21st century. Of particular note is Feder’s reading of the 2006 consensus statement of the U.S. and European endocrinological societies as simultaneously groundbreaking and unsatisfying in its failure to fully reject earlier taxonomies. For example, while the consensus statement does not advocate cosmetic surgery, it does suggest that such surgery might still be justified insofar as it offers “relief for parents” (43).

The underexamined role of parents in the treatment of intersex conditions leads Feder to a study conducted by Suzanne Kessler that found a tendency for people to reject gender reassignment for themselves but to agree to it when asked to “imagine their child” as born with atypical genitalia (44). Chapter 2 analyzes the implications of this study by bringing together insights from feminist ethics of care and Bourdieu’s analysis of the *habitus* in order to explore how common sense about gender formation impacts not only the lives of people with these conditions, but also their families. Drawing on her conversations with parents, Feder argues that recognizing the tension between “being attuned to a child’s needs, and wanting ‘what’s best’ for your child” is a necessary step in the process of parents learning to extricate themselves from “conventional wisdom” about what is best (62). Asking what else stands in the way of this identification, chapter 3 emphasizes the aesthetic and affective foundations of the decisions made by physicians and parents. Drawing on Nietzsche’s *On the Genealogy of Morality*, as well as work by Jane

Flax and Judith Butler on the loss entailed by assuming normative gender identities, Feder develops an account of the “unconscious wish to spoil the enviable ambiguity the bodies of children with atypical sex are taken to exhibit” (88). Acknowledging that this is not an easy argument to make, Feder nevertheless convincingly demonstrates that envy is a powerful tool with which to analyze the disgust and shame animating the scene of treatment. If bioethics sidesteps these complex affects too quickly, Feder argues, we will fail to understand the challenges standing in the way of a “corporeal generosity” (85), or an ethical orientation that could animate affects such as gratitude to disrupt the disgust and shame cycling through the management of atypical sex.

While chapters 2 and 3 seek to shift our focus to the bodies of those responding to the “problem” of intersex, chapter 4 seeks a deeper appreciation of the harms caused by the standard of care. It does this by pairing Merleau-Ponty’s account of the body schema with a first-person narrative about the effects of genital surgery on infants. This phenomenological analysis, Feder argues, should serve as a “supplement” to conventional approaches to bioethics (109). By directing us to the embodied experience of medical treatment and to the harms that take place at the juncture of the corporeal and the psychic—and are reducible to neither—this analysis allows us to understand “the material and symbolic harms that prevalent forms of evidence in the field inadequately capture” (91). Having laid the groundwork for the tools that might allow us to better understand the ethical violations perpetrated by the standard of care, Feder then returns to the question of why the thorough and excellent critique of these practices over the past several decades “has not resulted in change equal to that revelation” (110). Chapters 5 and 6 take up this question through analyses of culture and the new standard of neutral nondirective medical counseling, respectively. The critique of a medical claim to neutrality pairs especially well with Feder’s exploration into the extent to which we can understand ethical standards as cultural standards.

These questions about how to shift a culture (the habitus, or common sense, discussed in chapter 2) occupy the remainder of the book. In the final two chapters, Feder argues that the tradition of virtue ethics offers rich resources for shifting our understanding of what it means to parent ethically. This account focuses on the tension between control and vulnerability in parenting, insisting that “an unqualified promotion of parents’ desire to safeguard their children from all pain cannot be in their best interests” (165). Contrasting this account with other approaches

that emphasize family privacy, Feder then extends this critique to the notion of human rights. Relying on Debra Bergoffen's work on wartime rape as a specific ethical violation of a shared vulnerability, Feder argues that we must resist the marriage of autonomy and dignity often found in discussions of bioethics and human rights. This shift entails not only "[honoring] the dignity of the child's vulnerability" but also recognizing how the vulnerability of parents is wrapped up in decision-making about intersex conditions as well (192). The conclusion extends this meditation on shared vulnerability to the stories of physicians.

Feder's concluding argument about the need to better understand the harms caused by the attempt to ward off vulnerability is convincing. The stories of parents and physicians here lend a compelling depth to this ethical call. However, these final chapters also left me desiring a return to questions of history and power. How might an ethics based in a shared corporeal human vulnerability incorporate the insights of earlier chapters about the differential fields of power through which the lines of the human are drawn? Does this call risk flattening out the historical sense needed to understand why some bodies are seen as more dangerous than others? At the end of these final chapters, I was left thinking about why it is so difficult to be ethical (or perhaps simply philosophical at all, to recall her summons to philosophical parenting in chapter 7) when it comes to issues of gender, and the implications of this difficulty for an ethics grounded in shared vulnerability.

In this spirit, I would like to open up another line of inquiry. Following Feder's discussion of the affective and aesthetic foundations of medical decisions, what is the role of race in standards for genitalia? How might an account of the racialization of gender norms factor into the formulation of intersex as an ethical problem? Feder's rich work on disgust and shame in chapter 3 would lend itself well to an extended examination of how this history of race might be fueling anxiety about gender and sexual boundaries. I am thinking, for example, of María Lugones' work on "the organization of sex and gender under colonialism" and the grounding of racial hierarchies in the seemingly natural aesthetic standards of biological sex (Lugones 2007). While Feder does not engage with questions of race at length, the shift in perspective offered by her work invites us to pursue this connection as one that might give us an even fuller picture of the historical and often unconscious forces at work in the management of intersex conditions.

Making Sense of Intersex significantly enhances our understanding of intersex and the ethical issues involved in medical practice more generally. Feder's work urges us in particular toward a deeper engagement with questions of affect, power, and history, as well as attentiveness to moments where long-standing ethical principles do not go far enough in assessing harm. While she does not engage with transgender studies, her account of gender reassignment as harm will be of interest to scholars seeking to account for the harms of gender assignment in general. Her complication of the medical and social model of intersex could also be productively taken up alongside work in disability studies on the need to move beyond a potentially reductive account of this distinction. The book would work exceptionally well in introductory classes on ethics and gender, as well as advanced courses in applied ethics. I could also imagine assigning a number of chapters (especially chapter 3 on Nietzsche's *ressentiment*) as examples of how to use the tools of theory to look at contemporary social and political issues through different frames. While Feder tells us that she did not set out to answer the question of what good theory can do (16), her work here nevertheless gives us more than a few answers in this regard: shifting the discussion, opening up new lines of flight, questioning common sense, and demanding that "thinking practically" and thinking philosophically need not be at odds with one another.

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