How does a clinician determine what constitutes an ethical problem? In *Making Sense of Intersex*, Ellen Feder argues that cases that appear straightforward are the most likely to result in ethical violations. Regarding intersex surgical interventions, which are typically performed in infancy, Feder contends that clinicians often miss the ethical complexity of parental decision-making on behalf of children. Informed consent assumes an adult who can, with available information, make choices about their own body. For infants who cannot consent to surgery, however, how do parents and clinicians negotiate the boundaries of medical decision-making on behalf of infants? What are the long-term ethical implications of decisions to alter an infant’s body? As intersex adults have pointed out, their primary bioethical concern is not accessing needed care, but the ability to refuse interventions. Feder, a professor of philosophy at American University who specializes in bioethics, examines how assumptions about normalcy produce the need to conceal intersex bodies,
and how these assumptions result in shame and familial conflict. Throughout the book, Feder investigates intersex medical interventions from multiple angles, including the primacy of the child-parent relationship, the ethics of caregiving and consent, and the complex slippage that occurs when “good medicine” does not equate to “ethical medicine.” By composing an interdisciplinary analysis of medicine, *Making Sense of Intersex* can be read with interest by medical providers, bioethicists, and medical humanities scholars.

*Making Sense of Intersex* begins with an historical account of atypical sex/intersex as a medical category. Feder claims that the development of the Standard of Care (SOC) for intersex is not a linear narrative of progress towards ethical treatment of intersex patients. Building upon the work of Alice Dreger, co-founder of the Intersex Society of North America, Feder argues that contemporary fascination with “hermaphroditism” (an anachronistic term for intersex) can be traced to the Victorian period, when intersex first became a medical category, and intersex people became objects of fascination for clinicians. Nineteenth-century attitudes towards intersex individuals were connected to conservative ideas about gender and sexuality, to the expansion of medical authority, and, through military exams given to British colonial forces, to the subsequent “discovery” of the high prevalence of intersex individuals. During this era, the first genital surgeries were performed, albeit at the request of consenting adult patients (Dreger, 1998). In the early twentieth century, care of patients with congenital adrenal hyperplasia, an intersex diagnosis with concordant medical needs, was connected to medical need and patient autonomy. In contrast, the development of SOC practices in the mid-twentieth century more closely followed conservative Victorian-era attitudes by emphasizing aesthetic surgical intervention. Feder posits that the modern insistence on surgical intervention for atypical genitalia relies upon an ahistorical perspective, and thereby ignores the ways in which intersex people have lived happily without cosmetic surgical interventions in other eras.

Feder proceeds with a discussion of the infant-parent bond. SOC
for intersex diagnoses is fraught because it requires clinical decision-making on behalf of an infant. Using Bourdieu’s concept of *habitus*, that is, the unquestioned frameworks that guide cultural structures, Feder discusses how such assumptions generate an imperative for normalcy, thereby creating situations wherein parents who want nothing but the best for their children can do significant harm. Such decision-making requires that parents imagine what life might be like for their newborn infant as an adult, sexual being. Parents must make a decision for their infant that is “in their child’s best interest,” but are likely not equipped with the medical knowledge or caregiving experience to do so. By engaging with feminist scholarship on motherhood and Kleinian psychoanalytic theory, Feder suggests that motherhood necessitates attentive care and interpretive skills to anticipate a child’s needs. Anticipation of these needs is predicated on parental identification, the idea that parents are able to see themselves in their child, and therefore interpret their needs based on a *priori* knowledge from life experience. Because sexual difference is of such primary importance in Western conceptualizations of the body, parents of intersex infants are unable to imagine themselves as their child, a future intersex adult, and instead project a desire for normalcy onto their child as an adult who does not yet exist. In the case of intersex infants, Feder contends that surgical interventions without the patient’s consent represent a failure of parental identification.

Feder then deliberately “turns the lens” from intersex patients to clinicians, arguing that the assumption of a clinical imperative to conceal intersex bodies stems not from medical need but from projected provider disgust. A series of qualitative interviews with medical doctors follows an innovative approach in the intersex literature that allows for insight into the medical decision making process and the assumptions underlying it. Feder offers perceptive analysis of these conversations, concluding that for clinicians involved in the care of intersex infants, a “normal” appearance, with all of its presumed social rewards, takes priority over the sexual pleasure and at times the medical need of an intersex infant. Proponents of genital surgery in intersex infants maintain they are helping
their patients avoid shame. However, we must consider the source of shame by asking who provokes it; shame and disgust are implicit when families are instructed to change their child and to keep their diagnosis a secret. Feder concludes instead that we should relocate the “imperative for change” from the bodies of intersex infants to the providers that care for them.

While critics in the West often cite genital circumcisions in sub-Saharan Africa as coercive, they take for granted or ignore infant intersex surgeries performed in the West. Feder (2014) addresses this paradox by arguing that aesthetic genital surgery on intersex infants may represent a “difference of degree rather than kind (p. 127).” Citing ethnographic work among the Kono of Sierra Leone, who practice circumcision as a rite of adulthood that allows for political participation in society, Feder argues that Kono initiation is similar to Western surgical practices in intersex infants, differing only in that it is required of everyone and is a public ritual, while in the West genital surgeries are required of only a few and are considered private and shameful. Criticism of non-Western practices relies on a false dichotomy rooted in colonialism that describes Western practices as medical and therefore necessary, and non-Western practices as primitive and therefore unwarranted. However, Feder (2014) suggests, “practices that have been well-established are not the result of careful…reflection, but instead are a matter of repeated enactment of cultural values…” (p. 132). In insisting on the modification of an infant’s body, those who promote genital surgeries are in effect suggesting that it is more important to change an individual’s body than it is to change a society that insists on a gender binary.

In the latter half of the book, Feder asks why, if SOC for intersex infants has changed drastically in the last twenty years, has the rate of infant genital surgeries remained the same? Many providers state that early genital surgery is “what the parents want.” This sentiment mirrors previous arguments for infant surgical intervention that assumed parents would be unable to bond with a child with atypical genitalia. The second half of the book questions these assumptions and offers an analysis of
power in parent-child and patient-provider relationships to the study of bioethics. Informed by psychoanalytic interpretation of the parent-child bond, Feder analyzes a series of qualitative interviews with parents of intersex children. She argues that the parent-child bond is one of interdependence, that is, parents don’t just shape their children, but are in turn shaped by the act of parenting. Feder similarly turns to the patient-provider relationship, suggesting that physicians help to shape reality for their patients; the provider assumption that the intersex SOC represents guidelines for “what is” rather than “what should be” represents a refusal to acknowledge the unequal power dynamic between provider and patient.

Alternative conceptions of time are implicit throughout Making Sense of Intersex. The birth of an intersex individual creates urgency in the minds of providers, while simultaneously forcing parents to re-imagine their child’s future. Embedded in the argument for aesthetic surgeries for intersex individuals is the idea that individuals with atypical genitalia cannot have a future, or that their only possible future is tragic. In fact, Feder begins Making Sense of Intersex with a critique of the 2000 statement by the American Academy of Pediatrics, which states that the birth of an intersex individual represents a “social emergency.” Feder’s framing of the implicit beliefs underlying the “emergency” of an intersex body parallels arguments posed by feminist disability studies scholars such as Alison Kafer and queer studies theorists such as Jack Halberstam about the role of time, particularly “futurity” in conceptualizing non-normative bodies. Their work considers similar bioethical questions in the context of prenatal genetic counseling and violence against transgender people, making significant contributions to discourses on non-normative bodies. Feder’s work would have been strengthened by engagement with these existing critiques of bioethics, power, and violence. Likewise, Making Sense of Intersex offers feminist disability studies and queer studies additional tools for discussing the medicalization of embodied difference. Ultimately, Feder, Kafer, and Halberstam are all asking the same question: who gets to decide which bodies are anomalous—and, ultimately, will such bodies be allowed to exist in the world on their own
terms?

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References


Bio

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