Putting the ethical tools of philosophy to work, Ellen K. Feder seeks to clarify how we should understand “the problem” of intersex. Proposing a philosophical framework for the treatment of children with intersex conditions—one that acknowledges the intertwined identities of parents, children, and their doctors—Feder presents a persuasive moral argument for collective responsibility to these children and their families.

ELLEN K. FEDER teaches philosophy at American University.

“Ellen K. Feder’s exploration of the ethics of intersex treatment is a cautionary tale for health care providers and families. She makes it clear that the prevailing model of decision-making for irreversible treatments such as surgery and hormonal therapy relies on the flawed premise that these treatments will prevent harm to children and families. Assuming that information overload will paralyze anxious families, physicians fail to provide balanced education on long-term effects. In dismissing input from the ultimate experts, patients with lived experience of lasting physical and emotional trauma, clinicians neglect their primary moral obligation to vulnerable families. As a physician, mother of adults with atypical sex, and moderator of a family support group, I strongly urge clinicians involved in the care of these children to read this book.”

—ARLENE BARATZ, MEDICAL ADVISOR, AIS-DSD SUPPORT GROUP

“Ellen K. Feder expertly employs the tools of the medical humanities to examine the thoughts, desires, and growth potential of the parents and clinicians who care for children born intersex—with sex chromosomes, hormones, or body parts that don’t quite match medical standards for males or females. Rather than the usual and often misguided emphasis on gender identity development and its attendant politics, Feder focuses instead on how parents love and how clinicians care. The result is a powerfully sympathetic and deeply moving call to a better way for all of us.”

—ALICE DREGER, NORTHWESTERN UNIVERSITY

“Just when you thought nothing more could be added to intersex scholarship, Ellen K. Feder, a compassionate philosopher, uses the tools of her discipline to expand our understanding. Drawing on chilling stories of the treatment of children with ‘Disorders of Sexual Differentiation,’ she tackles questions like: What constitutes good medical care? Why are children’s needs subverted? What underlies the compelling appeal of normality and aversion to intersexuality?”

—SUZANNE KESSLER, PURCHASE COLLEGE, SUNY

“Linking the problems raised by treatment of the intersexed to problems that are endemic to the field of bioethics, Ellen K. Feder argues that, in seeing itself charged with the task of solving specific case problems, bioethics has abandoned its philosophical mission of examining the ways that these case problems are framed and neglected its obligation to critique the context within which bioethics is asked to operate.”

—DEBRA B. BERGOFFEN, AUTHOR OF CONTESTING THE POLITICS OF GENOCIDAL RAGE: AFFIRMING THE DIGNITY OF THE VULNERABLE BODY

“An important book for bioethics as well as theories of gender and sexuality. A gripping narrative with clarity of purpose and ease with major philosophical approaches to ethics and sexuality.”

—CYNTHIA WILLET, EMORY UNIVERSITY

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This is for Zoey and for Enza
(as Nic said)
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Introduction

Disciplinary Limits: Philosophy, Bioethics, and the Medical Management of Atypical Sex

“THE BIRTH of a child with ambiguous genitalia constitutes a social emergency.”
So begins the statement published in 2000 by the American Academy of Pediatrics (AAP) titled “Evaluation of Newborn with Developmental Anomalies of the External Genitalia.” What the AAP means by “social emergency” appears to concern the emotional confusion and distress that parents may immediately experience upon learning they have a newborn with atypical sex, meaning a sex anatomy that is neither clearly male nor clearly female. “Words spoken in the delivery room,” the statement continues, “may have a lasting impact on parents and the relationship with their infant.” It is especially important that medical personnel take care in discussions of “the infant [who] should be referred to as ‘your baby,’ or ‘your child’—not ‘it,’ ‘he,’ or ‘she’” (2000, 138). As damaging as a mistaken assignment of gender would be for the parents and the child is the kind of treatment that denies the infant’s personhood. We may readily appreciate the difficulty parents and medical professionals face when they are so challenged by an infant’s anatomy that they risk causing harm to the child and to the relationship between the child and those charged with caring for the child.

The term “social emergency” conveys the urgency of a situation that can effect considerable damage to the vulnerable child and to the fragile—for newly forming—bonds between parents and children. Without saying so outright, the AAP’s description of the birth of children with ambiguous genitalia as a social emergency expresses the apparent, and apparently obvious, discomfort that atypical sex generally provokes. But the term also raises the question of the place of medicine in addressing a matter not of medical urgency, but of social urgency. In seeking a response to this question, perhaps we may be guided by the AAP’s statement itself, which goes on to detail the variety of diagnostic and surgical tools that may “fix” the problem of sex that bodies with ambiguous genitalia present.

Contemporary French philosopher Luce Irigaray famously opens her book An Ethics of Sexual Difference with the claim that “sexual difference is one of the major philosophical issues, if not the issue, of our age” (1993 [1984], 5). While I think many people believe that the urgent status attributed to the birth of a child
with atypical sex gives truth to, or perhaps exemplifies, Irigaray's claim that sexual difference is the problem of our time, each of the chapters that make up this project treats the medical management of atypical sex not as a problem of sexual difference, but as a problem of ethics.

There is no mention of ethics or ethical treatment in the 2000 AAP statement concerning the treatment of newborns with ambiguous genitalia. This is hardly remarkable, since there is little explicit discussion of ethics in medical literature concerning treatment of most any other condition. It appears that, for many, it goes without saying that good medical care is "always already" ethical medical care. But perhaps the identification of "good" care with "ethical" care is too quick. However skilled or nuanced, a fair amount of medical practice could be described in mechanistic or technical terms, something we may hesitate to describe in ethical terms at all (the language of "compliance" seems more apt). Describing something as "not ethical" may confuse matters, however, for we tend to think that such a characterization somehow implies that something is unethical—in other words, that it violates accepted ethical principles. It is probably fair to say that most physicians are like the rest of us with respect to the conduct of our professional and personal lives. We do not, as John Stuart Mill pointed out, actively and continuously question our motives and scrutinize our behavior; instead, we rely on habituated tendencies—for example, in treating others with respect. We tend to believe that we know what is right and that we will act in ways that conform to what Immanuel Kant called "the moral law."

But because of the confidence that most of us have, and on which we rely, it can be difficult to appreciate where we might go wrong ethically, especially when our actions—and the understandings that ground those actions—are thoroughly embedded in what we might describe as a "social sense" of what is right and good. As perhaps no era more than our own has taught us, it is precisely in the failure to identify an ethical problem as an ethical problem that grave violations may occur and be allowed to persist. In the case of atypical sex, serious ethical violations have occurred in the course of the development of the "standard of care," which has functioned to treat a social problem as a medical issue. Accepted medical practice in the care of individuals with atypical sex anatomy is intended to conceal the variation of sex anatomy—something that occurs far more often than most of us have been led to believe. Over the last sixty to seventy years, physicians have recommended and performed genital surgery and gonadectomy and prescribed hormone replacement specifically to normalize the bodies of infants, older children, and young adults with atypical sex. The concealment of atypical sex anatomy that these interventions aim to achieve, I argue, makes of the bodies of those with atypical sex "the problem" when we should better see 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.

Those working in the humanities or social sciences are often asked—sometimes repeatedly—how it is that they came to be working on whatever comprises the subject of their research. Given the range and sometimes obscurity of the areas of our work, the question is not unexpected. I too want to know, for example, how someone decided to write her dissertation in anthropology on the experiences of Guatemalan foster mothers of children who will be adopted in the United States, or why another became interested in the mid-twentieth-century history of Puerto Rican beet farmers in Michigan. Why the fascination with "bourgeois compassion" in Victorian novels? The question may be merely polite or may express genuine interest; it may also be a way of asking why anyone but the author should be interested in someone's research. Why is it important or interesting or significant? What is to be gained from it? For those of us who have worked in various ways on the ethical problems of the medical management of atypical sex, the question may also be prompted by a baser sort of curiosity concerning our own embodiment, or perhaps that of someone close to us—a sibling, a partner, a friend. It may also be a question provoked by suspicions or worries about what could motivate someone's interest in such bodies, especially when the person asking is someone with an atypical sex anatomy or the parent of a child with atypical sex anatomy.

I understand these suspicions. When Margaret McLaren, a senior colleague and friend I had admired for years, called me in the spring of 1999 to ask that I participate in the first panel on intersex at the American Philosophical Association, it took me only a moment to say no. It wasn't that her invitation was unwelcome or inappropriate somehow. She knew I had worked for some time on the development of the diagnosis of gender identity disorder in children. It is also possible that we had spoken years earlier about my teaching of social psychologist Suzanne Kessler's groundbreaking 1990 article, "The Medical Construction of Gender: Case Management of Intersexed Infants." Like almost every other feminist I knew, I regularly included this article in the courses in feminist theory and women's studies I taught as a graduate student in the early 1990s.

Drawing on interviews with physicians she conducted in the late 1980s, Kessler brought to light the rationale guiding decisions about sex assignment in the cases of children with ambiguous genitalia, an area of medical practice that was almost entirely unknown outside of medicine at that time. The prevailing standard of care meant that nearly every child born with atypical sex anatomy—including 46,XY (that is, chromosomally typical) males whose penises fell short of the standard of one inch—would be reassigned female. It meant that a girl with complete andro-
gen insensitivity syndrome would be told by her endocrinologist that her “ovaries weren’t normal and had been removed . . . [he] told her that she could marry and have normal sexual relations . . . [that] uterus won’t develop but [she] could adopt children” (S. J. Kessler 1990, 230). She would not be told that she was genetically male, but because her body lacked androgen receptors, her physical development took a path that made her look, and (probably) feel, like a girl. Instead of a uterus and ovaries, she was born with testes that, absent those androgen receptors, had not descended. Doctors make treatment decisions, Kessler wrote in her 1998 book, Lessons from the Intersexed, “on the basis of shared cultural values that are unshared, perhaps even unconscious, and therefore considered objective rather than subjective” (18).

Many of us spent a lot of time through the early 1990s arguing about the "construction" of gender and asking what it meant to see gender as constructed. Judith Butler’s Gender Trouble (1990)—published the same year as Kessler’s article—was a frequent topic of our reading groups. We taught Kessler’s article not only because it was so accessible to our students but also because it upset the distinction that had taken hold of feminist thinking by that time, namely, the distinction between gender as “social construction” and sex as a product of “nature.” It was even this difference, we instructed our students (and ourselves), that required “problematization”: We trained students to critically examine this concept that functioned as an unspoken foundation for action and understanding. Instead, they should see this seeing this taken-for-granted thing as a question meriting exploration and interrogation. Kessler’s analysis of the doctors’ belief that sex was something they could manipulate demonstrated how it was not only gender that was affected by social thinking: in the case management of intersexed infants it became evident that even sex—supposedly natural, stable, fixed—could be a matter that was “decided.” Historian Thomas Laqueur’s Making Sex: Body and Gender from the Greeks to Freud (1990), also published in what was evidently a critical year in thinking about sex, showed us and our students that thinking about the putative “immutability” of sex had a much longer history.

My research project—what eventually became Family Bonds: Genealogies of Race and Gender (2007)—took shape in the context of this discussion. My interest in gender identity disorder was motivated by my effort to understand the kind of power that “produced gender,” that made gender make sense as a category of difference. The production of gender was different from the production of race, I argued, and if we were to appreciate how gender and race worked together as categories of difference, as they were in fact experienced in people’s lives—another focus of the thinking of the early 1990s—it was important to see how they functioned differently, how they were the products of different kinds of power. If our bodies were the place where those expressions of power came together in individuals’ and communities’ experiences, a more finely tuned understanding of how these expressions of power differed could provide a means of talking about gender or race (or gendered or raced experience) in ways that did not promote exclusion of one category at the expense of the other.

My project was a theoretical one. It sought to make a case for how the work of twentieth-century French philosopher Michel Foucault could be used to understand the workings of these different kinds of power and their effects. The project applied Foucault’s method in recounting histories intended to illuminate these different operations of power. Between the stories of the founding of the first middle-class suburb of Levittown, New York, and the story of a federally financed effort to coordinate genetic and biological research into the causes of “violent behavior” was the story of the development of the psychiatric diagnosis of gender identity disorder (GID) in children. GID is a diagnosis that, starting in the 1970s, began to be treated, first primarily in little boys who acted like little girls and soon thereafter to little girls who acted like little boys. By the application of Foucault’s concept of power was helpful in understanding the operation of GID, it seemed to me that the normalizing practices involved in the medical management of intersex conditions could not be so neatly described in these terms.

All this is to say that I didn’t refuse Margaret’s invitation because I didn’t know anything about the medical management of intersex, or because I didn’t care about it. In fact, Kessler’s long-awaited Lessons from the Intersexed—which remains, fifteen years later, a landmark book—had just been published, and I had eagerly read it. I refused Margaret’s invitation because I didn’t think the work I had been doing on the question of power and the production of gender was of any use in thinking about what was going on at that moment in people’s lives. The fact that Margaret prefaced her request by telling me that the impetus for the panel had been a conversation with Cheryl Chase, the founder of the Intersex Society of North America, who would also participate, only confirmed for me that I had no place speaking on such a panel, which I immediately understood would need to address current practices as they affected those with atypical sex and to make criticism of those practices central to the analysis. The work that I had done focused on historical cases for the purposes of making theoretical points; it might be—and like most people working in social and political philosophy, I hoped it could be—relevant and useful for social and political thinking and action. My primary aim in examining the cases described in the emerging literature on gender identity disorder was not to expose or criticize practices associated with the creation of the diagnosis (though there was no doubt that I found that aspect of the work gratifying); these cases served the purpose of clarifying or arguing for theoretical points; they were instrumental to my analysis, not the focus of it. But in the case of the treatment of intersex, the relationship between theory and what was going on at that moment in people’s lives needed to be reversed: rather than the cases serving the theory, the theory needed to serve the cases. And besides, I
didn’t see what I could add to what Kessler—and to what Alice Dreger, the historian who had published the year before an excellent ethical analysis in the Hastings Center Report (1998a)—had already done so well.

That’s a long way of explaining why I declined Margaret’s invitation. She understood, she told me, and we said good-bye.

A few weeks later Margaret called back and told me, “You have to be on the panel; I can’t find anyone else.” Well, all right, then, I thought. I still didn’t think that any of my previous work was really useful for thinking about intersex, and I knew that I couldn’t treat intersex as another “case.” So if I was going to think about what philosophy could contribute to critical thinking about the medical management of intersex, I had to start from scratch. But Margaret told me I would have nearly a year to prepare my paper. Because this was a panel at the American Philosophical Association, it struck me that figuring out what—or maybe whether—philosophy had something to say had to be the task.

This book is the result of my trying to answer that question of what philosophy has to offer, a task that has occupied me—and with which, many can attest, I have been preoccupied—for almost fifteen years. I began by asking what I thought philosophers working in medicine, biomedical ethicists, had had to say about the medical management of intersex, and I was surprised to find that the answer was, nothing. I found this silence especially surprising in light of what began to seem like routine violations of some of the most thoroughly investigated problems in medical ethics, especially the question of deceiving patients. But the reason—or reasons—why bioethics had had nothing to say surprised me even more. I soon learned that my assumptions about biomedical ethics, as well as the role of philosophy within the field, were not well informed. I did not sufficiently understand the contemporary history of my own profession, which included the “confinement” of philosophy in the wake of the McCarthy era that John McCumber discusses in his article “Time in the Ditch: American Philosophy and the McCarthy Era” (1996), and I was completely ignorant of the history of the formation of bioethics.

Philosophy in the History of Bioethics

Beginning in the 1950s, philosophy would be restricted, McCumber writes, to “second-order inquiry . . . [that] also carried through in ethics. Philosophers of the day were not to take ethical stand or give moral advice but simply to reflect on the meaning of ethical terms” (2001, 38). Contemporary work in applied ethics might appear to constitute an important departure, and indeed its entrance into the field coincides with some significant changes. Rather than seeking “truth,” the initial aim of applied philosophers generally, and bioethicists in particular, was to put the tools of philosophical analysis to work. Their goal, in the parlance of the sixties, was to give new “relevance” to philosophy. Albert Jonsen’s account of The Birth of Bioethics (1998) traces the shift from the strictly metaethical analysis that counted as “ethical philosophy,” to the “new vitality” of applied ethical interrogation, to the “public agony” provoked by the Vietnam War. Jonsen relates that consternation over the war and its implications peaked during the years 1968–1969 and “swarmed,” as he writes, into the ordinarily sedate annual meeting of the Western Division of the American Philosophical Association . . . [with] Noam Chomsky . . . had been invited to open a symposium entitled, “Philosophers and Public Policy.” After delivering a stinging attack on the American government for its pursuit of the war and for its imperialism, and on the general dominance of a power elite wielding technological mastery that it proclaimed to be “value-free,” Chomsky challenged the audience of philosophers: “These are the typical questions of philosophy . . . philosophers must take the lead in this effort.” (1998, 75)

Jonsen rightly observes that “only a non-philosopher could believe that such issues had been ‘typical questions of philosophy,’ at least during its recent history.” It is not surprising that Chomsky’s exhortation met with strong resistance from the philosophers present. John Silber pointed out the error of Chomsky’s characterization of his discipline. “As philosophers,” he said, “we can assist in the formation of sound public policy by distinguishing appropriately different kinds of ethical theories and kinds of moral and political obligation” (quoted in Jonsen 1998, 76).

But some philosophers would embark on a new beginning in the early 1970s. No longer could the kinds of ethical violations marked by the Holocaust, Hiroshima, and the McCarthy purges themselves go all but completely ignored by philosophers. Questions of human rights brought to a head by Vietnam and the civil rights and women’s liberation movements (the latter of which is almost never acknowledged in histories of bioethics) would come to the fore, and new questions would be raised by the growing technologies of the life sciences. At the same time that philosophy was seeing a kind of revival, bioethics as a discipline began to take shape. And yet it is not entirely clear to what extent the changes in philosophy bear upon, or are themselves influenced by, the development of bioethics.

Most historical accounts of bioethics trace its origins to the public revelations, beginning around 1965, of unpalatable practices that were common in human experimentation after the Second World War; some involved injections of live cancer cells or “artificial induction of hepatitis” into unsuspecting patients; a good deal of research involved experimentation on the senile and elderly, as well as mentally retarded adults and children. The disclosure in 1972 of the forty-year-long Tuskegee syphilis experiment, examining the effects of untreated syphilis in nearly four hundred poor black men to determine the long-term effects of the disease (Jonsen 1993; Reverbry 2009), also spurred federal regulation. That same year saw news reports of radiation experiments in Cincinnati that over the previous
twelve years had exposed more than eighty mostly indigent, black cancer patients to radiation—not for therapeutic purposes, but in the interest of national defense (Stephens 2002). In the utilitarian terms in which doctors were then schooled, the practices were justified by the extraordinary understanding and array of therapeutic products that resulted from these studies (D. Rothman 1991, 79). In the wake of increasing revelations of the questionable use of human subjects, the National Institutes of Health (NIH), which was funding much of the work, and the U.S. Food and Drug Administration (FDA), with a mandate of "consumer protection," grappled with what sort of standards to apply to human research, making distinctions between therapeutic and non-therapeutic research, invigorating peer review, and providing the first standards concerning consent (91–92). Toward the end of the decade, Princeton philosopher Paul Ramsey began to study the problem of human experimentation. Experimentation involving human subjects, as David Rothman puts it in Strangers in the Bedside, "presented an unavoidable conflict of interest. The goals of the researcher did not coincide with the well-being of the subject; human experimentation pitted the interests of society against the interests of the individual. In essence, the utilitarian calculus put every human (subject) at risk" (1991, 96).

Doctors came under increasing scrutiny not only because of questions of human experimentation but also because of scarcities created by the limited availability of new technologies. In 1960 a Dr. Scribner in Seattle, Washington, developed a "permanent indwelling shunt" that would permit patients with advanced kidney disease to be connected to a dialysis machine. With far fewer machines available than eligible patients, Seattle doctors were faced with the dilemma of who would live and who would die. Daunted by the prospect of making such decisions—and finding themselves in a position where a doctor's imperative to "do everything possible to enhance the well-being" of his patient might be impossible (D. Rothman 1991, 151)—a committee of what were described as "quite ordinary people" was appointed by a county medical society and charged with making the decisions the doctors declined to make. Reflecting on the ethical problems posed by the committee's own decisions (which involved preferences for churchgoers and married men with children over single women, for example), a public lesson in the need for "principles or guidelines" was learned (152).

Philosophers began to be summoned to help doctors respond to these questions posed by fast-expanding research programs, new technologies, and the scarcities and liabilities they engendered. This call culminated in the founding of the Hastings Center, located in Garrison, New York, in 1969 (Stevens 2000, 48). The center (originally called the "Center for the Study of Value and the Sciences of Man") was the first organization dedicated to the advancement of bioethics. Its decision to stand independent of and unaffiliated with any university or professional school was motivated by a view that such an organization must remain "outside" the institutions whose practices it would examine. The vision of its founder and until 1996 its president, Daniel Callahan, was a grand one, infused with the critiques of technology associated with thinkers such as Herbert Marcuse. It would confront the problems emerging from "advances in the life sciences [that] pose social and ethical questions touching the fate of individuals and societies, now and in the future. The common phrases 'biological revolution,' 'population explosion,' and 'environmental crisis' only hint at the terrible complexity of these advances and the problems that follow in their wake" (Callahan 1970, cited in Stevens 2000, 51). Despite the lofty vision of the Hastings Center's leading lights, accounts of bioethics' origins make clear that even if the new field was not precisely intended to function as the pleasure of medical practitioners and to respond to fast-multiplying queries from "legislators, educational institutions, parties to pending litigation, and others seeking advice and assistance" (Stevens 2000, 56), satisfying the new demand for answers would nevertheless come to function as the center's mainstay and as its most important source of ongoing financial support (59).

In the inaugural issue of the Hastings Center Studies, Callahan published the first effort to define the emerging field. In "Bioethics as a Discipline," he writes, "The discipline of bioethics should be so designed, and its practitioners trained, that it will directly ... serve those physicians and biologists whose positions demand that they make practical decisions" (Callahan 1973, cited in Jonsen 1998, 326). Certainly, applied ethical theory should serve practitioners. But in the case of bioethics, and clearly as the example of the medical management of atypical sex indicates, the specific nature of that service—to supply guidelines and to seek answers to questions framed by practitioners rather than pose independently formulated questions (see also Jonsen 1998, 333)—brings scrutiny.

One of the forms that these "answers" has taken is the adumbration of principles that would guide practices; early discussions of bioethics focused on the positing of these principles. These would famously take shape in The Belmont Report, produced at the end of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (begun in 1976 and appearing in final form in the Federal Register in 1979), as respect for persons (autonomy), beneficence (and non-malfeasance), and justice (see Jonsen 1998, 333, 103–104). Where Chomsky exhorted philosophers to ask questions, then, bioethicists have, in the years since the field's first emergence, largely limited themselves to providing answers to questions that they are not permitted to pose themselves. Instead of promoting a critical stance toward the scientific enterprise, bioethicists have been required to occupy a supporting role, to become, as Callahan glumly characterized bioethics' role in a 1996 article, "good team players" (Callahan 1996, cited in Stevens 2000, 73).

Examining the history of bioethics helped me to better understand how it was that bioethicists had not intervened in the unethical treatment of children with atypical sex. But it was not at all clear to me that there was anything I could
do about it. At the same time, as I had remarked in my panel presentation, much of what makes intersex conditions threatening is not a matter of scientific understanding or careful reflection, but issues from that unreflected realm of knowing, of what is taken for granted, that has been the object of the work of philosophy since Socrates. When at the end of the session at the American Philosophical Association, intersex activist Chase leaned closer to me and said, “You need to do more. It’s time that philosophers say something about what’s happening.” I thought she was right, but I also thought, “What could that be?”

Telling Stories: History and Method

It would make for a better story if I could report that I experienced some sense of personal mission from that moment, but what occurred between that panel and today probably looks a lot like how many other book projects come about, in fits and starts (and a number of stops along the way). What would make this work different for me was my understanding that however much theoretical analysis this thinking demanded, I wasn’t working on a theoretical issue, but on practices that affected people who had experienced violation of their bodies and senses of self. Children and adults had endured a kind of suffering that was obviously wrong. But if history is any indication, that suffering would be repeated and would spread as more specialists were trained in the United States, Europe, and all over the world. So Chase was right that philosophers needed to say something about what was happening. I am not sure it will make any difference, but I began to feel, and have felt ever more strongly since, an obligation to try to say something, to use the tools of philosophy to make sense of what is happening, to make arguments about what I think is wrong and why, and to try to envision a way forward. This project is my effort to do just that.

Unlike much work in philosophy that examines ethical problems in medical practice, my work makes use of the tools of philosophy in the continental tradition—that is, philosophy that works from thinkers from France and Germany—as well as from thinkers in the more extended history of Western philosophy. It also makes use of empirical research that I conducted myself. The former stems from my graduate training and to the teaching I do now, but the latter came about as a result of the limits on the primary source material that would help me understand the ethical problems the management of atypical sex anatomies poses.

Just at the time I was writing that first presentation for the APA panel in 1999–2000, I was working with Eva Kittay, who had been my mentor as a graduate student, on a project on the ethics of care and questions of dependency, particularly what Kittay describes as the “secondary” or “derivative” dependency of one whose caring for a dependent other renders the caregiver vulnerable. It was the coincidence of what initially seemed entirely separate projects that led me to ask how we might better understand the extraordinary character of the medical manage-
that I had published feminist work that made obvious the “direction” my research would take.\textsuperscript{11}

I felt terrible. However “honest” my mistake, it seemed to me that the ire I had provoked was a measure of the vulnerability that had motivated my question. Rather than a better understanding of that vulnerability, I had managed only to aggravate it, and with it the pain and distress these parents felt. I really didn’t have any business doing this sort of work. But that anger, and perhaps also the repeated expression of fear in the posted threads—not so much for the health of the children, many of whom faced genuine medical challenges, but fear that their children might turn out to be gay—turned out to be the real beginning of the work I had proposed. Just when the members of the Listserv declared an end to the project before it had begun, one adult with atypical sex sent me a one-line e-mail message that read, “My mom will talk to you.” That mother was the woman I call Ruby, in chapter 2. It was hearing her story that made me feel that I really needed to write that article, and it is her story to which I have returned most frequently over the years that I have been working on this project.

We initially spoke by phone, and I had intended to travel to meet her in person. However, having not spoken about the protracted ordeal she had experienced with her daughters, who had each been announced male at birth, she began to tell her story and didn’t stop until it came out. I’ve never written so fast, and as the story spilled out of her, I worked to blink back my own tears. When we hung up I knew I had to write her story immediately, not only because I wanted to capture her voice, which I could still hear, but also because I knew I might not be able to read my own barely legible writing the next day. I sent her what I wrote and she made minor corrections, adding details about long car rides with her two young children.

A couple of years later we finally met face-to-face, along with her two adult daughters, and we have maintained sporadic contact over the years since. I spoke with other parents that year, mostly in person but also by phone. I recorded our conversations with their permission and transcribed our conversations using pseudonyms. Three of the families who did not participate in that Listserv contacted me after being alerted of my request by friends or acquaintances who had seen my posting; other families were parents of adults I had gotten to know.

It would be a few years after publication of the work on parents and dependency that I decided to go forward with completing a book. However, I had no intention of pursuing additional interviews for the project I then envisioned. I had sought the opportunity to speak with parents when I did, because I could find no other means of pursuing the questions I was asking with respect to dependency and care. Since completing that first essay, a wealth of first-person narratives and new scholarship in anthropology and sociology would, I believed, make any forays I might make into social scientific research unnecessary.

It wasn’t until 2010–2011—more than two years after I had planned to complete the book I thought I was writing—when I was trying to find out to what extent the new recommendations that came in the 2006 “Consensus Statement on Management of Intersex Conditions” (hereafter referred to as the Consensus Statement) by the U.S. and European endocrinological societies (Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology, respectively) had actually changed the standard of care, that I would again find it necessary to seek permission to talk to people as part of my research. I spoke with pediatric specialists in urology, endocrinology, gynecology, psychiatry, as well as psychology—twelve in all—who treated children with atypical sex anatomies and who could tell me more about whether any changes had been made in related clinical practice since 2006.\textsuperscript{12} These conversations told me a great deal about how care had—and had not—changed; they also yielded a number of surprising insights into the conditions of the possibility of changes in practice that significantly shaped my arguments in chapters 5 and 6.

It was while talking to physicians about their experiences with parents faced with making decisions about the care of their children that I began to have questions regarding the nature of the potential harms brought about by surgeries that physicians recommend and perform. Published narratives of individuals who have had normalizing genital surgery, as well as accounts collected by social scientists, provide evidence that both physical and emotional harm has occurred as a result of these surgeries. But these accounts provide little detail concerning the specific nature of that harm or what have been characterized as multiple harms. It seemed to me that the failure to investigate these harms had implications for efforts to secure truly informed consent from parents regarding normalizing genital surgeries for their children. I needed to talk not only to those who had experienced this harm but also to some of them who would share with me the work of thinking about it.

Since that first panel at the American Philosophical Association, I had worked in nonacademic settings with individuals who identify themselves as intersex activists. The informal conversations I had had over those years suggested something of the nature of the harm that is not recorded in current research. I asked two of those individuals—Jim and Andie—who I first met separately more than ten years ago, if they would be willing to think about what is meant when we talk about harm resulting from the medical management of atypical sex. Each of these conversations was in some respects a lot like the initial conversation I had had with Ruby, but they also differed in that I was asking these individuals not only to recount their stories but also to try to identify what they meant when they talked about harm. These were difficult conversations. The thinking that is reflected in the chapters in which their stories appear (chapters 4 and 5) is a result of their analysis, together with mine, and like so much of the work of this project,
it moved in directions I could not have anticipated when we began these conversations.

I also did not expect to have the conversations I did with the mother whose story appears in chapter 7. She and her husband reached out to me and to Alice Dreger following the publication in *Bioethics Forum* of short essays we had written. The first essay criticized questionable research practices involving the administration of dexamethasone to women at risk of giving birth to girls with congenital adrenal hyperplasia (Lindemann, Feder, and Dreger 2010). The second described the work of a pediatric urologist who was conducting genital sensitivity exams on young girls after surgical reduction of their clitorises in infancy, usually those with the same condition (Dreger and Feder 2010). Sonja and her husband wanted to tell their story in part because they wanted to record for their daughter the decisions they had made and the reasons for those decisions. When I spoke with them, I did not anticipate that our conversations would provoke yet more questions for me—concerning the ethics of parenting, autonomy, dignity, and human rights—which would result in the addition of what would become chapters 7 and 8.

Over the course of this project I came to understand that the conversations that I had had over these years constituted fragments of oral history. It wasn’t that I was trying to write history or conduct a sociological study, but in order to understand what questions philosophers should be asking, I needed insight into the meanings of decisions that had been made, to understand the assumptions that guided the practices of physicians and the parents they advised, and to learn more directly than the literature provided the consequences of these practices. At the same time, following Foucault, I saw that the questions I posed should be informed by what he called a “history of the present” (1979 [1975], 31). My research into the history of bioethics had already revealed my misunderstanding of the work of bioethics. A similar history lesson could help make sense of what was meant by hermaphroditism, intersex, or “disorders of sex development,” and how these meanings had changed over time. In addition to the personal narratives I had gathered, I needed a broader understanding of the history of medical practices regarding people with atypical sex anatomies and the medical thinking about these individuals.

* * *

We know that terrible violations of ethics are often recognized only in retrospect; for that reason, ethicists must take history seriously. Attending to the historical development of the standard of care that sought to make individuals’ sex of assignment consistent with their body’s appearance is essential for understanding the ethical questions that standard poses today. Chapter 1, “The Trouble with Intersex,” traces the changing views of the stories of “the problem” of atypi-
framework that allows us a transformative view that directs us to shift our focus from the bodies of those born with atypical sex anatomies, which have been the privileged objects of attention both in medical practice and in criticisms of it, and moves us to consider instead the bodies of those whose responses constitute the motivating force for normalizing practices in the first place. This chapter is at the center of the text because the question it seeks to address is what I take to be the most confounding question posed by the medical management of atypical sex: what can account for the urgency "to fix" children in ways that have been demonstrated to promote harm rather than flourishing? This question becomes more confounding still, I propose, when we take into account the fact that we know there are individuals whose atypical sex anatomies have not been medicalized. And yet the sort of criticism that Nietzsche offers does not suggest a simple response, or, put another way, it doesn’t provide direction in a manner that can be readily articulated within the terms of the discussion of the medical treatment of atypical sex anatomies today. That is to say, there is not an obvious way of tackling the issue of resentment head-on. Thinking practically (as is ultimately my goal), one may reasonably ask how to combat (an unconscious) resentment in parents, doctors, even society? The inability to do so may lead one to conclude that if the philosophical analysis Nietzsche offers cannot lend itself to a direct response, what good is it?

It was not my principal aim to respond to the question of what good theory in the continental tradition could do. Nevertheless, I found that the work of Bourdieu and Nietzsche offered tools for understanding how the standard of care that made surgical and hormonal "normalization" of children’s atypical sex anatomies come to be regarded as necessary, and why, in the face of compelling arguments for change, these beliefs persisted. The work of these thinkers did not, however, offer obvious resources for sharing that change. What might be characterized as the defensive tackling of "the problem of intersex"—what I suggest we see in terms of Nietzsche’s concept of resentment—has not proved as successful as intersex activists once hoped. I propose that what is required is a kind of offensive end run of the sort I develop in the final chapters of the book, which focus on the ethical construction of meaningful change. Before moving to the possibilities for change, however, we must understand the nature of the harm effected by that standard, to consider more carefully the role of culture in the development of both the standard of care and challenges to that standard, and to know more about the clinical practices that continue to promote a medical treatment that has resulted in harm.

The harm inflicted by the medical management of atypical sex anatomies has now been documented at considerable length. Physicians, parents, and patients agree that physical and psychological injury has resulted from castration and sex reassignment in boys with micropenis, as well as from clitorectomy or clitoral recession in girls with a ditoris determined to be "too big." Uncomfortable or pain-ful vaginal dilation in young children following vaginoplasty or the construction of a neovagina, repeated genital exams, and medical photography have produced trauma. There is also emotional harm caused by the intentional misrepresentation of a condition or procedure and the insistence that parents maintain the secrecy of a child’s atypical sex from the child and extended family. But the enumeration of harms may have proved insufficient to convey the nature of the injury.

In chapter 4 I propose that French phenomenologist Maurice Merleau-Ponty’s concept of "the body schema" offers a resource for a deeper appreciation of the violation that normalizing interventions for atypical sex anatomies effect. This concept encompasses the ground for Merleau-Ponty’s understanding of who and what we are as embodied subjects, which is neither reducible to nor separable from our somatic being. Merleau-Ponty (1956 [1945]) makes much of what he calls the "ambiguity" of our human being as subject and object, perceiver and perceived. In his view, human consciousness cannot be understood purely as a function of cognition, of "I think that," but should be conceived instead as an embodied consciousness, of "I can"—that is, what I am able to effect—in order to engage in the world and with others. For Merleau-Ponty, thinking and understanding are never separable from our being in the world, in culture and society, and among embodied others. If this phenomenological approach helps us to better appreciate the experience of Jim, who had been born male and was reassigned female as an infant, and that of his sister, Mary Katherine, who was not informed of Jim’s history until she was an adult, I think it is because Merleau-Ponty’s thinking about our embodied consciousness provides a means of thinking about harms that are inadequately described in the limited—and limiting—terms of "the physical" or "psychological" to which we usually resort.

Although I had initially spoken with Andie to gain better understanding of harm, our conversation led me to consider more carefully the way that "ethics" may be understood to figure in the care of children with atypical sex anatomies. The extent to which a conception of ethics is continuous with the rules of "culture" was something I had begun to explore in chapter 2, but Andie’s account provided the impetus to reflect in a more considered way how cultural rules or expectations may conflict with ethical imperatives. In the bioethical literature, questions about the role that cultural difference may play are more frequently discussed with respect to intercultural difference—for example, when the cultural expectations governing patient care in a given context are at variance with expectations of a patient’s culture of origin. Intracultural rules and expectations of the sort that Bourdieu discusses are more rarely a source of conflict or worry, as they proved to be in the case of atypical sex anatomies in children in the West at least since the 1950s.14

This tension between the rules of culture and those of ethics may explain why physicians’ accounts have come to increasingly portray parents as “demanding”
or "insistent on" surgical intervention. I wondered how changes announced in the 2006 Consensus Statement had transformed care. Based on the conversations I had with physicians in 2010–2011, chapter 6 provides a good idea of the state of care at this time. Physicians’ accounts of their discussions with parents of children born with atypical sex anatomies for which surgery is an option demonstrate changes consistent with the recommendations of the Consensus Statement. Rather than providing clear recommendations in favor of normalizing surgery, however, doctors now appear to provide what is known as "nondirective" counseling. Analysis of the apparently value-neutral options that involve what is presented as a choice between either aggressive and active medical intervention aimed at securing a child's well-being or "doing nothing," as one clinician has put it, may contribute to parents’ experience of urgency or certainty with respect to decisions to pursue surgical intervention.

My discussions with doctors at this time coincided with my meeting of Sonja and her husband, Elias, whose careful thinking about parenting their daughter, Shai, evoked a tradition of moral reflection grounded in what philosophers call virtue ethics. Sonja and Elias’s reasoning stands in stark contrast to what was in 2010 the most developed statement of an "ethical" approach to normalizing interventions for children with atypical sex anatomies, produced by the German Bioethics and Intersex Group. My criticism of the limits of this approach through the moral framework employed by Sonja and Elias forms the basis of chapter 7. Privileging the question of parental rights, the approach of the Bioethics and Intersex Group fails to promote both the well-being of children with atypical sex anatomies and the bonding that is in the best interests of parents and children alike.

Chapter 8 extends the analysis begun in chapter 7 to develop a more detailed philosophical ground for the concept of human rights implicit in the approach of Sonja and Elias. It makes central the ethical value of human vulnerability and investigates what duties are entailed in what contemporary philosopher Debra Bergoffen describes as the obligation to honor the "dignity of the vulnerable body." The conclusion of this project is dedicated to the stories of those physicians whose reflection on their medical practice is a moving demonstration of the recognition of this obligation and what we may hope is the promise of change already under way.

1 The Trouble with Intersex

History Lessons

In a short talk he delivered in 2000 at the American Association for the History of Medicine, pediatric endocrinologist Jorge Daaboul reflected on the revelatory character of history in his own practice. He recounts that he had begun to have serious doubts about the standard of care that made imperative the surgical normalization of atypical genitalia in children. Though this was the standard in which he had been trained—in the tradition of Lawson Wilkins, the founder of pediatric endocrinology, and John Money, the preeminent psychologist of sexual difference—he began to pose to his colleagues the questions he had come to ask himself, namely, whether the standard was genuinely in the best interests of their young patients. The uniform responses to his questions, he told his audience in 2000, yielded two arguments in defense of the standard. First, "intersexed individuals," his colleagues told him, "could not possibly live normal lives as intersexed individuals and...the only chance they had for happiness and psychological well being was the establishment of a secure male or female gender identity. Second, there simply was no precedent for [such individuals] living as normal people in our society" (Daaboul 2000).

Just at the time that he was engaged in these conversations, Daaboul went on to say, he read Hermaphrodites and the Medical Invention of Sex (Dreger, 1988b), Alice Dreger's account of the Victorian "discovery" of hermaphroditism. From Dreger's history he learned that until the late nineteenth century, individuals with intersex were not automatically objects of medicine as he had been trained to see them; until the start of what Dreger calls the "Age of Gonads" (1870–1935) (29), people with atypical sex anatomies in England and France lived unremarkable lives. It couldn't be, Daaboul realized, that it was necessary to correct the bodies of individuals with atypical sex in order to secure their happiness. The category of "the normal," which he had been trained to see as natural and necessary, was all at once a historical artifact. "For me," he concludes, the study of history proved invaluable in my formulating an approach to intersex. The moment I realized that there was a historical precedent for individuals with intersex leading happy, normal productive lives I revised my approach...and have become a strong advocate of minimal intervention. The study of the history of intersex gave me the knowledge to improve and refine
action. The group’s reproduction of the opposition between (vulnerable) children and (autonomous) parents restricts the question they can ask to the permis-
sibility of parents’ consent to normalizing surgery.

If we see instead that parents and children are both vulnerable, and that their
dignity as vulnerable bodies is truly shared, then it no longer makes sense to see
the ethical question as concerned first or only with respect to the permis-
sibility of surgery and parents’ authority to consent to or even to seek surgery on behalf
of their child. Instead, we must make obligation the focus of our attention, that
is, we must ask how the duty to honor the dignity of the child’s vulnerability may
be fulfilled. It seems to me that if we ask the question this way, parents of children
atypical sex would not have the experience that Sonja and Elias report having
with specialists in the care of children with conditions like Shai’s, an experience
that in many respects looks much the same as it did twenty, thirty, or even fifty
years ago. Instead we would ask how best to secure the connection to their child,
that is, how to support parents in their duty to honor the dignity of the child’s
vulnerability, and to help them to see early in their child’s life what most parents
will understand only after many years: how the dignity of their child’s vulner-
bility is also their own.

Conclusion

Lessons from Physicians

Perhaps particularly in medicine, discussions of ethics today have become
increasingly difficult to distinguish from discussions concerning “legality.” Ask-
ing about what is right or good can too easily become a question of what is per-
missible or what constitutes culpability. Returning to ancient and early modern
sources of ethics, as I have proposed in the last two chapters, may serve to remind
us that, while ethical concepts or frameworks figure prominently in the law, ques-
tions concerning what is ethical or moral are not identical with those concerning
what is legal. So many practices in which we engage in our lives are matters of rich
ethical reflection falling outside the realm of legal regulation.

When I began researching the history of bioethics fifteen years ago, I was sur-
prised by the incongruity between the conception of what was in medicine called
“ethics” and the understanding of ethics that I had received in my training in
philosophy. Many disciplines have been developed for—and are well suited to—
crafting answers to questions. But philosophy is first and foremost a discipline de-
veloped to ask questions. If we do not ask why we think as we’ve been taught, or
why we do as we’ve been trained or as we have become accustomed, we will take
for granted that what we think is true and what we do is right. Just as important,
as Socrates first demonstrated, is asking whether the questions we ask are the right
questions. Do they move us to consider or investigate what is important, vital,
true, consequential? Are the questions informed questions, themselves grounded
in knowledge that is reliable? And, we should ask, why do we ask the questions
we ask? For what purpose, to what end, and for whose benefit do we ask them?

What it means for philosophers to consider “the problem” of intersex—that
is, to understand the ethical significance of the treatment, both medical and so-
cial, of those with atypical sex anatomies—is to consider both what questions are
asked and what questions are not asked and why. In retrospect, I think it was my
awareness that I didn’t know much at all about atypical sex or the experience of
those who had been subjected to normalizing interventions that led me to think
about how the tools of philosophy could be put to work to understand what has
motivated treatment and to clarify the nature of the wrongs that have occurred.
The point with which I continued to struggle, and that I had put aside, was the
question of change. It was not so clear to me what role philosophy could play in
changing the standard of care.
The series of conversations I had with the parents Sonja and Elias directed me to return to the ethical tradition of the ancient Greeks for guidance in thinking about how we might understand the possibilities for change in the care of children with atypical sex anatomies. Through this lens I began to return to some of the conversations I had had with physicians about their practices and began to see that perhaps I had been asking the wrong questions.

When I sought out physicians to learn what was occurring in their clinics, the questions I would ask, as I had assured my university’s Institutional Review Board, would be limited to those concerning how parents of children with atypical sex anatomies were counseled in the clinics where they worked. It had not occurred to me that during those conversations any of the physicians would spontaneously offer what I came to recognize as a form of testimony. Their stories revealed awareness of their own fallibility, of the mistakes they had made, or in which they felt implicated as doing harm. But in these stories, too, was a recognition of what I came to understand as the dignity of vulnerability that was so important for understanding the problem of intersex. Rather than ask how philosophy could play a role, then, perhaps the tools of philosophy could be most effective in identifying how ethical reasoning was at work in change that had already begun.

Dr. Spruce’s Story

During our conversation about the kind of counseling parents of children with atypical sex anatomies are given today, Dr. Spruce began to think out loud about why he thought change in the prevailing standard of care had proved so difficult. Physicians and medical researchers are not only committed to their work; they are also identified with a line of investigation or innovation that they have inherited from their teachers and will, they hope or expect, project forward as their own legacy. Maybe it is for this reason, he says, that “I don’t think they put a lot of energy into exploring the errors in judgment that they have made . . . They can’t disconnect from what they have said is right.” Admitting error is difficult, he was suggesting, because it was not just about a single mistake but also threatened a whole lineage of work to which one belonged, that was bound up with one’s sense of self and of one’s value.

Dr. Spruce took his own experience as a case in point. He saw his own error when a teenager seeking to transition to male came to the clinic where Dr. Spruce worked. Reviewing the teenager’s record, Dr. Spruce saw that he himself had participated in the decision to reassign the teenager’s sex to female as an infant.

“Did the teenager seek you out?” I asked.

“No, it was worse than that,” he said. “He didn’t know that I had been involved in his care as an infant. And I wound up telling him that.” The experience made Dr. Spruce look again at “situation after situation where I . . . declared with a kind of impunity that my assignment of gender was correct. And I can actually remember standing over an infant in a bassinet with a urologist across from me, and saying, ‘This kid’s phallus is too small for him to ever be a real man. Let’s make him a girl.’”

Dr. Spruce is not the first to be made aware of an error in sex assignment in which he participated, nor to be told that the normalizing surgery he recommended had caused harm. But he is one of the few who seems not to have sought to conceal or deny that mistake. At the time of our conversation, I did nothing to prompt the specific revelation of his encounter with the teen and the effect that encounter had had on his view of normalizing surgeries. I had asked to talk to him to better understand how counseling had changed since the publication of the Consensus Statement in 2006; I did not expect him to talk about his experience as he did. I understood that part of what made it possible for him to see his error was timing: between the founding of the Intersex Society of North America in 1993 and the consensus meetings in 2005, there was, as another physician put it, a sea change in general awareness about, and recommended treatment of, atypical sex. This was largely due to ISNA’s organizing, which inspired revelations by affected individuals of their experience and the harm they—and sometimes their families—had endured. The powerful critical narratives and analysis these affected individuals, along with academic allies (some of whom were also individuals with atypical sex), produced prompted some physicians to question the medical practices standardized in the mid-1950s. Doubts that this collective work had planted were reinforced and more widely publicized by the revelation of David Reimer’s experience just a few years after ISNA’s founding. But as marked as these changes have been, the majority of specialists have continued to take normalizing surgery to be in the best interests of children and their families.

Considering the context in which Dr. Spruce remarked on his encounter with the teenager in our conversation, his explanation of his colleagues’ resistance to investigating their own mistakes provides insight into why it was that this experience had a significant effect on his understanding. If his colleagues are reluctant to admit error, it may be because they resist disruption of their sense of self, tied as it is to their work, and the connection they understand this work—and themselves—to have, often to the past, and almost always to the future.

In my discussion with him, there was no sense that Dr. Spruce was unsympathetic toward his colleagues; his willingness to admit error was not an assertion of superiority on his part, but it nevertheless acknowledged a difference between himself and those colleagues for whom the admission of error would constitute too great a threat. His sense of self was located not in the sort of legacy attached to discovery or breakthrough, perhaps, but in his sense of mission as a physician, as someone who understands medicine as a practice of caring for others’ health and well-being. Such a commitment requires that a mistaken practice be cor-
lected, not denied. The younger Dr. Spruce, who unhesitatingly reassigned sex, might have regarded that standard recommendation as common sense—which for so many physicians, beginning in the late 1960s or early 1970s and continuing through the mid-1990s, it was. The teenager’s return to the clinic brought to the seasoned Dr. Spruce undeniable evidence of bad judgment. But I would guess this was not the first experience of “unlearning” he had had in his career or in his life. I don’t say this from any intimate knowledge of him but from what I have gathered in the closer study of virtue ethics to which my discussions with physicians like Dr. Spruce have led me.

Foucault’s discussion of the work of virtue can help us to understand the changes in Dr. Spruce’s thinking. Foucault identifies in Plato’s treatment of Alcibiades, a young statesman preparing to lead his fellow citizens, the starting place for a study of the care of the self. Alcibiades’ capacity for care for the city depends, Foucault says, on his ability to care for himself. The two directions in which he must “concern [him]self with . . . justice,” Foucault reminds us, “apply[ ] both to the soul and to the city” (2005 [2001], 174). In the Alcibiades, where Foucault locates “the founding of all philosophy” (189), we see the ways that care of the self and care of others are—must be—connected. It is not possible to care properly for others without caring for oneself, and each expression of care also serves the other. Alcibiades must learn that leading his fellow citizens well will allow him to “benefit from the prosperity of all and from the salvation and victory of the city that I have ensured” (176). The Alcibiades emblazonizes the ancient notion of care of the self in its emphasis on the pedagogical work that promotes self-care: in his insistent and annoying interrogations of himself and of all those around him, Socrates proves the exemplary teacher who insists that we attend to ourselves.

Foucault explains that the importance of pedagogy on display in the Alcibiades “tends,” after Plato, “to give way to other functions” made salient in the work of Stoics like Seneca. Undertaken over the course of a life such as Dr. Spruce’s, the incident with his returning patient suggests the operation of these “other functions” in the care of the self. Foucault identifies, first of all, a “critical function”: “The practice of the self,” he writes, “must enable one to rid oneself of all one’s bad habits and all the false opinions one may get from the crowd or from bad teachers, as well as from parents and associates. To ‘unlearn’ (de-discere) is an important task of the culture of the self.” In Dr. Spruce’s case this unlearning would only be possible with the second function, what Foucault characterizes as the “struggle” that care is understood to involve, and for which one must be equipped not only with weapons but also with courage (495).

The function of struggle is one to which we should devote some attention. Foucault’s emphasis on the importance of struggle in the care of the self is echoed in the discussion of “the curling parent” in chapter 7. The cultivation of the virtuous character depends on learning how to navigate obstacles and to overcome difficulties. And yet, as Sonja and Elias experienced, parents faced with decisions about normalizing their child’s sex anatomy may be encouraged to neglect this sort of moral education with respect to not only their child’s development but also to their own, as parents. In studying virtue ethics we learn that failure to recognize the salience of struggle in moral development is a failure to understand the nature of virtue; indeed, finding ourselves drawn to the “easy path,” we may see any difficulty or challenge as an indication that that course of action is wrong. In Dr. Spruce’s account, one may gather that he had taken for granted the idea that normalizing atypical sex was the right thing to do. This confusion is understandable, as one of the continuities between virtue ethics from the ancient Greeks and Romans and utilitarianism is that the end of moral philosophy is eudaimonia, the human flourishing we call “happiness.” If a course of action does not result in happiness, or what we take to be happiness, we will understand an action to be—or to have been—wrong.

It is possible that one could see Dr. Spruce’s experience in utilitarian terms, as a matter of failing to promote happiness. And yet I think he would understand the wrong in which he repeatedly participated, and in which the majority of specialists in DSD continue to participate today, as wrong not only because it resulted finally in unhappiness but also because it constituted a deeper violation than he could have recognized at the time. The problem existed with both his action and his own inability to engage in “reflective scrutiny” (Hursthouse 1999, 166), a capacity that depends on the development of the practical wisdom he would likely characterize as lacking when he was a younger man. Rather than focus on moral actions and their consequences in narrow terms—what I think we should understand as a kind of crude utilitarianism—virtue ethics demands that we focus on the moral agent, and on the development of the moral character of the agent who can exercise the practical wisdom necessary to make sound decisions and reckon with the difficulties and engage in the struggle that life will bring.

The critical functions of care of the self and the struggle in which the moral agent must be engaged over his life, together with the courage these require, are necessary for carrying out what, for Foucault, may turn out to be the signal activity of moral life, namely, telling the truth (parhesisia). In Foucault’s account, truth-telling, or “speaking freely,” is the willingness and the deliberate decision to say what one believes to be true (2005 [2001], 372). But this is not just any truth. It is one that involves criticism, whether of self or of others. Such criticism, Foucault goes on to suggest, entails danger, some form of risk to one’s self (2001, 16). One incurs this risk to fulfill a moral duty “to improve or help other people (as well as oneself)” (19). Admitting error in medical practice poses a considerable legal risk today, one that, as recent articles on the subject indicate, may explain what appears to be an increasing prevalence—or perhaps simply the revelation of a long-standing prevalence—of physicians avoiding telling patients what we
might call "the whole truth." In Dr. Spruce's frank account of his experience, we can see the operation of each of the functions of the care of the self that Foucault enumerates, perhaps especially the ways in which his admission exemplifies the third, "curative and therapeutic function" of care of the self. It is fitting that the function of the care of the self (epimeleia heautou), promulgated by thinkers of later antiquity, is "much closer to the medical model than to the pedagogical model" (Foucault 2005 [2001], 496) of Plato. If it is not clear whether the objects of the curative and therapeutic work that such care of the performed are those affected in some way by DSD—individuals with DSD or their families, those who have already been or have yet to be treated—or whether it is Dr. Spruce himself, I think it is because, for virtue ethicists, we must consider these as linked. As Dr. Spruce is not only a practicing physician but also a medical educator, the subjects of this therapeutic work must include those patients who have not yet entered the clinic, as well as those physicians he is training now, and for whose development he also takes responsibility. Learning to be a "good" doctor, he demonstrates, involves confronting one's own imperfection. Dr. Spruce's success as a teacher of doctors will not be measured by his students' stubborn unwillingness to admit error or to see decisions in the stark terms as either right or wrong, but by his students' ability to listen to those they treat in their own practice, by their capacity to honor the dignity of their patients' vulnerability that, no longer the arrogant young doctor in his thirties, Dr. Spruce recognizes is also his own.

Dr. Maple's Story

It is easy to see how it could be that Dr. Spruce could experience a sense of responsibility to his patients and to his students, a responsibility that extends also to himself and to his profession. Dr. Spruce's story is easily located in the history of the medical management of atypical sex. This history is usually recounted as a history of those whose bodies, lives, and professions have been indirectly affected by, or have had a role in, the medical management of atypical sex. Unlike Dr. Spruce, Dr. Maple was not a specialist in DSD care when she began her career; her endocrinological research in the mid-1990s, focused on molecular biology and androgen insensitivity syndrome as a genetic anomaly, provided valuable insight into evolutionary biology. But soon after the publication of her research, a founding member of the fledgling Androgen Insensitivity Syndrome Support Group contacted her to ask if she would attend the inaugural meeting of the North American extension (which would become AISSG-USA) of the group that had started a few years earlier in the United Kingdom.

We all met in New York City. It was summer, I believe. It was hot, and we were scheduled to meet in a university building. It was a Saturday, so we had to be let in through sort of a back door by a security person, and we surreptitiously made our way up what seemed to me—in my memory anyway—a dark

and winding back stair, into this small, enclosed room that seemed to be very hidden away. There was an air of secrecy and trepidation. As I think back, it seems that the women wanted very intense privacy because of their emotional state about their condition at that time.

We sat there in this quiet, otherwise empty room, maybe twenty people, all women. Most were women with androgen insensitivity syndrome or similar conditions. I think there was one mother. I was the only physician. We sat in a circle on wooden chairs and the women went around, one by one, sharing the stories of their diagnoses and how they had been treated by physicians and sometimes by their parents. They shared how they had eventually come to learn their diagnoses and various aspects of them, including their chromosomes and their history of having had tests removed in childhood or their teenage years, and for some, of having had surgeries performed on their genitalia. For some, the most painful memory was having been examined by multiple people, and for others it was having been lied to by doctors and parents. There were lots of pauses and silences and tears and tissues.

What struck me intensely was how poorly so many of these women had been treated by the medical profession. I felt this great sense of responsibility. And remorse. And in some way guilt, for the harm that had been brought upon them by my colleagues. I felt, from that point forward, a kind of bonding with this group of women and then, by extension, with anyone with these conditions. That experience gave me a sense of needing to make things better for these women—and hopefully for other children and affected individuals in the future—by helping physicians see different ways—hopefully better ways—of treating these individuals.

Aside from a disquieting but routine episode in medical school, when Dr. Maple was one of a number of medical students brought in to see a child with atypical genitalia—an episode she had preferred to forget—she had only limited clinical experience with individuals affected by DSD even during her fellowship in endocrinology. What occurred behind the closed doors of that New York City classroom was unsettling not only because of the anguish to which she now bore witness but also because she felt responsible for it. She had not been consulted in the cases of any of the women in that room. Unlike Dr. Spruce, who had confronted a mistake he had made directly, both in the case of the young man who had returned to the clinic for care and in the other cases much like that young man's, Dr. Maple's work had not been primarily concerned with patient care at all. The responsibility that Dr. Maple felt cannot be explained simply in terms of feeling implicated in the wrong of her profession. She suggests that guilt figured somehow. And yet her account suggests that it was not a sense of culpability so much as it was the attainment of a new knowledge—the truth of what women with AIS experience—that became the source of her feeling of obligation to the women in that room, to the individuals who were not present, and also to her colleagues in the profession.
At the end of the course at Berkeley that took up the question of truth telling or parrhesia, Foucault explains that the subject of his lectures had been what he describes as "the problematization of truth" that was at work from the beginning of the period Western philosophers identify as the birth of the discipline of philosophy and that, Foucault believes, must preoccupy us today (2001, 170–171). His investigation into the history of truth telling, he says, is not concerned with people's behavior or even with "ideas in their representative values." Rather than a social history, or a history of ideas, the historical analysis in which Foucault is engaged is intended "to analyze the process of 'problematization'—which means: how and why certain things (behavior, phenomena, processes) become a problem" (171; original emphasis). If the history of hermaphroditism in Europe and the United States of the late nineteenth and early twentieth centuries is the story of how and to what effect intersex bodies became a medical problem (Dreger 1998b; Reis 2009) for which normalization would be the answer, I wonder if the stories of Drs. Spruce and Maple, and the "critical attitude" they exemplify, mean that the history of the late twentieth and early twenty-first centuries will come to be understood as the period in which "the problem" of atypical sex began to be recast as a problem not of intersexed bodies, but a problem for "the rest of us."

Dr. Aspen’s Story
About halfway through 2011, Dr. Aspen was reflecting on how much had changed in the field. When she started in pediatric surgery, she explained, normalizing surgeries for girls with CAH were not a matter of controversy, and postoperative exams by a surgical team, mostly comprised of men, were routine. Sometimes, she said, it was necessary to force the legs of the girls apart to assess the success of a surgery. The practice may have struck her as out of the ordinary, but she had not challenged it. But then she remembers, she was asked to make a presentation to a patient organization in place of her supervisor, who was unable to do so that day. In preparing the talk, she read more about the nonsurgical aspects of CAH (including hormone regulation) and collected her slides, including information about standard sorts of surgeries and postoperative treatment with which she was more familiar. She had not expected the immediate criticism that her presentation received. Opposition came not only from the parents and the patient advocates there but also from the pediatric endocrinologist who was in attendance. Turning her head away from me for the first time in our conversation, her face registered pain and renewed surprise at the memory, and after a moment she said, "I really felt like I was slapped in the face." "But," she added, looking directly at me once more, "this is how I learned." What Dr. Aspen learned is that many people condemned the standard of care that she had been trained to uncritically regard as in the best interests of the children she and her team cared for. She also learned from those assembled that it was possible to consider the normalizing surgeries in which she participated in very different terms than she had before. She learned that she had a responsibility at once beyond and attendant to that responsibility to cultivate excellence as a surgeon—namely, a responsibility to engage in reflective judgment—that she had not appreciated in this way before.

In the weeks and months after my conversation with Dr. Aspen, it seemed to me that her response to the incident she described was not only a story about the kind of awareness and understanding that are necessary for physicians like her, and for Drs. Spruce and Maple, to change their own practices and those in the field, but that the story was also an object lesson of another sort. It was the response of an audience at a single presentation that altered the course of Dr. Aspen’s thinking and action. Of course, one might say—and judging from my own experience with her, I would agree—that it was entirely consistent with her character that she would take heed of the criticism she received that day. In the wake of that episode she came to understand that even though her intentions were good, the knowledge on which those intentions were based—the conception of the good—was flawed. But for any number of factors—her colleague’s schedule conflict or the willingness of that first audience member to voice criticism—Dr. Aspen might not have had the experience she had that day and so might well have continued unquestioningly to regard herself and her colleagues as the experts in care rather than the patients.

Dr. Aspen’s is a story that in some important respects is much like that of parents, most often new parents, who believe they have done the right thing by consenting to normalizing surgery on behalf of their children. It seems obvious—until perhaps suddenly it does not—that normalizing surgery and the routinized practices that accompany it, are in the child’s best interests. What she describes as the experience of being slapped in the face was a confrontation with her assumptions and, eventually, with a sense of responsibility for her failure to recognize and to criticize those assumptions.

In his later work on care of the self, Foucault repeatedly remarks on the affiliation that the ancient Greek philosophical injunction to self-care had with medicine and with it the close association between “self-knowledge” (gnōthi seauton)—the “essential condition of philosophical practice” (Foucault 2005 [2001, 170])—and the Socratic injunction to care for the self. For the ancients, the cultivation of self is a lifelong task that is both “a duty and a technique, a fundamental obligation and a set of carefully fashioned ways of behaving” (434). Turning to Foucault’s analysis, involving, as it does, readings of mostly neglected primary texts in ancient philosophy, for insight into the revelation of Dr. Aspen’s mistake might appear unnecessary or unnecessarily arcane. But I think Foucault’s effort to understand ethics as a way of living, and not—as it seems to be regarded by physicians and many bioethicists today—primarily as a tool for problem-solving, provides a means of appreciating what I believe to be the broader significance of Dr. As-
pen's experience. Confronting a different understanding and a different knowledge than she possessed, she investigated her own ignorance and found insight that allowed her to change her practice.

The Virtue of Regret and the Ethics of Self-Care

The common thread that runs through the experience of these three physicians is acknowledgment of their own ignorance along with regret for the harm that resulted from that ignorance. I understand much better than I did at the start of this project the extent to which ethical reflection requires recognition of, and tolerance for, untidiness, imperfection, and the mistakes we make. We make mistakes not only in failure or refusal to engage in moral deliberation—when, history tells us, the worst problems can arise—but also in our unwillingness to reckon with the complexity that this untidiness so often entails.

In the absence of negligence, mistakes do not constitute a moral violation. But that does not mean that mistakes made in ignorance or good faith should not occasion regret. It also does not mean that regret is an appropriate response only to what would be regarded as mistakes, as even decisions that can be described as the "right" decisions can—and in cases that involve the most difficult decisions almost certainly will—entail consequences that are lamentable, unfortunate, or even awful.

In her defense of virtue ethics, contemporary philosopher Rosalind Hurthhouse offers a vivid illustration of the moral danger that may result when we "cut ourselves off" from bringing in moral decision making this kind of regret, or what is called the "remainder" (1999, 47–48). Hurthhouse takes doctors as her example.

Although I am, personally, sympathetic to doctors rather than otherwise, one does hear occasional hair-raising stories about the arrogance and callousness of some. What people often complain about is not whatever decision the doctors made, but the manner in which they delivered it or acted on it. No expression of regret, no expression of concern over whether anything could be done to make it less likely that such decisions would have to be made in the future, having made (what they take to be) the morally right decision, they seem to think they can review their own conduct with complete satisfaction. But if someone dies, or suffers, or undergoes frightful humiliation as a result of their decision, even supposing it is unquestionably correct, surely regret is called for. (48)

In On Virtue Ethics, Hurthhouse is concerned with demonstrating the value of the Aristotelian approach for providing direction in moral decision making, but her criticism of approaches such as those dominant in medicine compellingly illustrates how such frameworks can work to restrict the scope of our moral judgment and so our capacity for moral engagement with others in the world.

What distinguishes virtue ethics from the most "influential strands in contemporary Anglo-American bioethics[,]... prioritizing logic and abstract rationality, and drawing extensively on the formalism of consequentialist, utilitarian, and rights-based approaches to ethics" (Scully, Shakespeare, and Banks 2006, 760), is its focus on the moral agent, and not solely on the rightness of a given action. The treatment of atypical sex anatomies in children by the German Bioethics and Intersex Group, as I discussed in chapters 7 and 8, provides an example of applied ethical thinking insofar as it illustrates the limitations of casting as primary the principle of (parental) autonomy for identifying the moral questions posed by the medical management of atypical sex anatomies in children. Boiling down the ethical question of assessment of "right action" (in this case the question of where to locate consent), the group cannot provide due consideration to the questions concerning social and familial obligation it has set aside in favor of answering how to respect "parental rights." It is not that the approach of the Bioethics and Intersex Group could not, using the tools of deontology, consider more carefully the importance of the regret that figures centrally in the accounts of Drs. Spruce, Maple, and Aspen. Hurthhouse grants that these approaches (with some direction from virtue ethics) could certainly do so. But the work of the Bioethics and Intersex Group is characteristic of a resistance to acknowledge the harm that individuals and their families began to reveal in the mid-1990s; refusing to criticize the imperative of normality, the group cannot examine, and therefore cannot address, the regrettable consequences that have resulted from following the dictates of this imperative.

Promulgations of unsupported theories of the development of gender identity (evidenced in the claim that a typically male child with micro penis could be castrated and raised as a girl, or that shortening or removing a clitoris will ensure a heterosexual orientation in a 46,XX female); early surgical techniques found to be flawed (such as colon vaginoplasties that not only fail but are also prone to cancer); insistence that a normalized anatomy guarantees happiness, or is a condition of its possibility in the face of otherwise certain unhappiness; physicians have maintained that given the limited knowledge available, the decisions to reassign sex; to perform normalizing surgeries; and to conceal from children, and sometimes from their parents, the "truth" about their chromosomes or the anatomies with which children were born were good decisions.

It is not that physicians have refused wholesale to acknowledge bad outcomes, however. For example, there has been substantial analysis of what urologists unfortunately call "hypospadias cripples." Hypospadias is a congenital condition affecting genetically typical males in which the urinary meatus, the opening that is typically at the end of the penis, appears on the underside or at its base. The comparatively robust evidence of the success of hypospadias repair has meant that criti-
cism of this intervention has not had as much effect as criticism of other normalizing interventions for atypical sex anatomies. Despite what has become regarded as the routine character of these surgeries, among those who have undergone repair there are also a number of patients who have had repeated and unsuccessful repair, leaving them with significant functional problems.

"Hypospadias cripples" has remained a term of art in the medical literature since its introduction in 1970 by urologists Charles E. Horton and Charles J. Devine (1970). One might expect that its use would have fallen out of favor by now; applied to a whole person, the term "cripple" is offensive, certainly, identifying the individual with a damaged part of one's anatomy. Indeed, it was the awareness of just this problem—that is, the identification of a whole person, "hermaphrodite," with the medical condition (Dreger et al. 2005, 732)—that prompted the change in nomenclature in 2005. However, the retention of the term may be more surprising for the way it calls attention to how the medical treatment of atypical sex anatomies can themselves cause—or even be the primary source—of what physicians regard as the serious damage to a sense of self that motivates the repair in the first place. In considering what Hursthouse views as the failure to take regret seriously in dominant models of moral reasoning, the continued and apparently uncritical reference to hypospadias cripples in the medical literature illustrates the consequences of this failure. It is not that the mistakes physicians have made—technical mistakes—are unacknowledged or not investigated. But if most physicians who continue to recommend and perform normalizing surgeries see these results as "regrettable," they see the problem in the bodies of those affected. Any regret is not such that it will, as Hursthouse puts it, "mar" the agent whose choices resulted in harm (1999, 74).

The unwillingness to see oneself as damaged by the decisions one makes, especially including what a virtuous agent would regard as the right decisions, given difficult circumstances constituting a dilemma, is understandable. We see how readily Socrates elicited from his interlocutors in the Protagoras the claim that we like to see ourselves as "good." Philosopher Alphonso Lingis could be quoting Plato some twenty-five hundred years later when he observes, "We want to see ourselves as ethical persons... Our actions are just, honorable. We like to think of ourselves as moral, concerned with standards of behavior based on a sense of right and wrong" (2003, 197). Hursthouse's analysis suggests that our interest in seeing ourselves as good actors may be promoted by the emphasis that dominant ethical theories place on determining the goodness or rightness of acts. This emphasis, she observes, encourages what she describes as a "tendency to overlook remainder" (1999, 47).

To overlook remainder is to deny the moral complexity that attends living in a world, the imperfection of which, Kant taught us, makes ethics necessary in the first place. Virtue ethics, more than deontology or utilitarianism, helps us to see that the aim of ethical agents is not to have "clean hands" (Hursthouse 1999, 71), if what is meant by having clean hands is the sort of complacency or self-satisfaction that the feeling of making the right decision can bring. For virtue ethics, moral reflection does not begin or end with the judgment of the goodness of an act or the intention that motivated it. It resists "the assumption that, in any case of moral dilemma or conflict, one side must be unqualifiedly morally right and the other plain wrong, an assumption that runs very deep in everyday thought" (45). Focusing on the moral agent, Hursthouse's approach is especially well suited for reflection on the objectification of moral challenges we face as embodied subjects in a damaged world, including those challenges posed by our efforts to deny our vulnerability.

Boy or Girl: Beyond an Ethics of Right or Wrong

The observations that Hursthouse makes regarding the neat divisions between right and wrong and good and bad, to which we may reflexively turn in everyday thought, also apply to the thinking that has shaped the standard of care and are perhaps especially evident in the responses to calls for change. Recall that after David Reimer's story was told, first in the 1997 article by Milton Diamond and H. Keith Sigmundson, and then in stories in the New York Times (Angier 1997) and in Rolling Stone (Colapinto 1997), there was some interest among physicians, albeit limited, in questioning the standard of care. Reimer's story was important not only because it marked a failure with respect to the putative evidence of the "optimal-gender theory" that had once supported normalizing atypical sex anatomies but also because it demonstrated so vividly the human stakes involved in such failures. This was a story of twins whose experiences seemed to have led inexorably to the tragic end of their lives, and of parents who endured years of doing what they were told would best support their children only to learn that they had not supported or protected their children as they intended. And it hardly ended there, for the misplaced faith in these devastating interventions, and the intransigence of those who had a vested interest in protecting the legacy of the sex and gender research conducted at Johns Hopkins, had implications far beyond the Reimer family.

In an atmosphere in which doubts about the standard of care are given voice, we can make historical sense of Dr. Spruce's acknowledgment of error and of his experience of regret. His was not, however, the "common sense" of his colleagues. An editorial by pediatric urologist Kenneth Glassberg published in the Journal of Urology in 1999 was more representative of specialists in DSD care at the time. While Glassberg, too, found the consequences of Money's most famous experiment regrettable, he condemned the conclusion that surgery—which he conflated with sex assignment—should be stopped. Asking if those who have had "successful assignment" should be "condemned to growing up as what would be inevitably
considered freaks by their classmates” (1999, 1309), Glassberg reasserted the imperative of normality that by this time had become the primary rationale for normalizing interventions for atypical sex in children, subsuming the previous concern about the risk to individuals’ psychosocial development that “ambiguous sex” was thought to pose. Despite the confidence Glassberg expresses with regard to the “successes” he claims, he nevertheless grants in this same editorial that there was insufficient evidence of those successes to justify that confidence.

Glassberg’s response—one that could have been written by any number of specialists over the decade that followed—reflects the shortcomings in moral reflection to which Hursthouse points—that is, the resistance to seeing decisions made with the good intention to spare children shame as “bad decisions” and to viewing those who made decisions resulting in harm as sullied by the actions they took. The candor Glassberg displays in his insistence that without normalizing interventions children with atypical sex will be “inevitably considered freaks” has been, indisputably, the most important motivation shaping the standard of care since physicians began to defend the treatment of atypical sex anatomy in the mid-1990s. This shift explains how atypical sex became figured as a problem of gender.

For those activists and allies who advocate the multiplication or abolition of the categories of gender, and for those physicians and parents who take for granted that children with atypical sex anatomy will be burdened by their stigmatic difference, there is a fervent belief that the most pressing questions we should ask about atypical sex and its management are those concerned with sexual identity. While it is true that a clear and unassailable division of the sexes has been taken to be foundational to social order, it is less clear that this division is important today in quite the way that it has been. The division of the sexes nevertheless remains the primary “structure,” the “structuring structure” that orders our social world. I think it was for this reason that—despite many and repeated assertions to the contrary—in its fifteen years of advocacy to change the standard of care, ISNA never sought acceptance of a “third sex,” or even, as Anne Fausto-Sterling (1993) proposed, a fourth or fifth sex, a suggestion that she later made clear she had made “with tongue-in-cheek” (2000, 78).

Surely it is a measure of how entrenched the prevailing views of sexual difference remain that the recognition of bodies that do not clearly heed to the standard for male and female could seem to require the creation of new categories or constitute an argument for the abolition of sexual difference itself. When the rules of a rigid system of sex and gender have resulted in so much harm, it may seem that abolition or a “way out” is the best or only means of righting the wrong—the innumerable wrongs—that have occurred. To adults whose bodies bear those scars, or to those who have been brought to consciousness of the damage that has been done, it can seem like the answer is—or can only be, as some second-wave feminists proposed with all of the optimism and earnestness of the age—to create a society free of gender. But utopian visions provide little support or hope for new parents of children with atypical sex anatomy who must envision a future for their children in which parents’ own desired connection to, and involvement with, their children makes sense in the here and now. The idea of raising a child with “no gender” implies a life in which their child either has no place or will always be in struggle.

Because the vision of a society free from the restraints of a rigid system of gender has not been realized, and because gender and sexual identity remains for most an essential feature of a sense of self, the “choice” faced by parents of infants and young children with atypical sex anatomy has perhaps not seemed like a choice at all. Presented as a decision of whether to provide the possibility of inclusion or of living a life on the margins, as a decision to do something to ensure one’s child a life where it may appear that options and choices are possible, or to do nothing and so guarantee a certain, and certainly miserable, existence, the mapping of right and wrong in the construction of the decision facing parents closely mirrors the construction of the ethical questions we ask when we focus on the question of “which action is right, x or y?” One answer is right, and one is wrong. The construction of the problem in these terms makes the decision to normalize a child’s body easy and puts the messy remainder out of sight.

What the construction of the questions also excludes is what has seemed like the obvious question that activists asked from the very beginning of the movement to change the standard of care. What if—as history and as parents like Sarah, Sonja, and Elias show us—children with atypical sex anatomy can be raised as boys or girls without normalizing surgery?

A Way Forward: Affirming Ambiguity

For several years it did not appear that change beyond that modestly outlined in the 2006 Consensus Statement was possible. But the independent 2012 opinions issued by the Swiss National Advisory Commission and the German Ethics Council demonstrate the real and present opportunities for changing the standard of care. Their recommendations do not rely on utopian possibilities, but address the immediate needs of children and their parents. They recognize how past practices have constituted violations of children’s rights to autonomy and bodily integrity and impeded the bonds between children and their parents for the sake of which normalizing interventions had been viewed as essential.

Detailing the problems, both in past and in still-current practices, both opinions call for a more nuanced view of medicalization, clarifying, for example, that "a diagnosis does not in itself entail any treatment or other medical measures" (Swiss National Advisory Commission 2012, 11). They echo the calls that for years have been made by ISNA and allied physicians that normalizing interventions on
reproductive organs be undertaken only where there is a "danger to life" or the risk of "serious and grave damages to a child's health" (German Ethics Council 2012, 16; also see Consortium on the Management of Disorders of Sex Development 2006a).

Precisely because rationales for normalization in the past have focused on parents, the Swiss and German opinions recognize the importance of the provision of parental support in the care of children with atypical sex anatomy. The recommendations for parental support made by the Swiss go further than formal statements have in the past to propose that such support be regarded as an integral component of treatment for conditions involving atypical sex anatomy in children. Because no provision currently exists for state medical support for treatment of parents, the Swiss opinion also recommends "that a legal basis . . . be established which would provide for a special obligation to cover counseling and support for parents" and that it be provided well beyond infancy (Swiss National Advisory Commission on Bioethics 2012, 17).

It is not that the importance of support for parents of children with DSD was ignored in the 2006 Consensus Statement. In an appendix the statement acknowledges that the "value of peer and parent support for many medical conditions is widely accepted, and DSD, being lifelong conditions that affect developmental tasks at many stages of life, are no exception." Peer support can help individuals and parents and their parents find "a feeling of normalcy" and can help parents "find the best quality care" (Hughes et al. 2006, 562). While the statement acknowledges the importance of such support, in other words, it is regarded as an adjunct to care. The difference between the approach of the Consensus Statement and the Swiss opinion, I propose, is a matter not so much of emphasis but of object. I do not mean to suggest that ultimately the object of care differs between the two: For both, care for the child is central. But apparently taking seriously "the possibility," as Alice Dreger puts it, "that the child is not the wound that needs healing" (2006a, 78), the Swiss opinion signals a change in the object of treatment. Where in the 2006 statement there is no question that the object of treatment is the body of the child with atypical sex anatomy, the Swiss opinion makes clear that in many cases of DSD, the object of treatment must be the parents, for whom education and support are necessary for the child's well-being as well as the parents' own.

The opinion by the Swiss National Advisory Commission also addresses the limitations of prevailing constructions of the ethical questions guiding treatment. For example, they take on the previously insoluble dilemma of where in time to locate a child's interests to establish a basis for decisions regarding sex assignment: is it the present or the child's future that should be most salient? Where that question has proved to stymie moral reasoning, and has even been set aside as unanswerable, the Swiss acknowledge the difficulties the question must entail and assert what should be obvious, namely, that "determination of the child's welfare should be based as far as possible both on the current interests of the child and on the anticipated interests of the future adult" (Swiss National Advisory Commission 2012, 12; emphasis added). There is no attempt, in other words, to simplify the questions posed by the medical treatment of atypical sex. They do not set as their task resolution of the problem that atypical sex anatomy in children have been taken to pose. As a result, they avoid the trap of trying to solve—or resolve—an "ambiguity" that cannot be corrected or concealed.

In a dramatic reversal of the logic guiding the prevailing defense of the standard of care, the Swiss emphasize that "if interventions are performed solely with a view to integration of the child into its family and social environment, then they run counter to the child's welfare" (13). Where the problem of intersex has previously been located in the anatomy of children with atypical sex anatomy, the Swiss opinion sees the problem instead as a violation of the obligation of the state and by the families to their vulnerable children. In other words, what guides the opinion is not a determination to provide an answer to what has been posed as a conflict between parents' rights versus children's rights, or between the variety that nature offers and society's insistence on conformity to a norm; instead, it is guided by an effort to recognize the harm that has occurred and to outline the steps necessary to avert that harm in the future.

Forthright acknowledgment of the harm that normalizing surgeries may effect, and have already effected, leads both the Swiss National Advisory Commission on Biomedical Ethics and the German Ethics Council to see these harms as violations of human rights. Both make recommendations for reparation for the harm caused by normalizing interventions "which, given today's knowledge," the German Ethics Council argues, "no longer meet medical standards, and which have caused continuous suffering or a reduced quality of life for those so affected" (German Ethics Council 2012, 164). However, this is not to say that mistakes will not be made in the future. The clarity of the focus on obligation leads the German Ethics Council to take steps to address the harms that cannot be anticipated today and for which reparation may be necessary. Accepting that the decisions we make cannot be perfect, and that knowledge and understanding is never complete, the German Ethics Council recommends that comprehensive documentation of all treatment of children should "remain accessible to all concerned for at least 40 years," and that statutes of limitations be extended in the case of "irreversible impairment of fertility and/or sexual sensitivity" in order to provide the opportunity to recognize harms that have been committed, even with the best of intentions.

The work of the German Ethics Council and Swiss National Advisory Commission demonstrates the promise of the kind of ethical engagement that makes acknowledgment of remainder central to moral reasoning. If we are able to bring
that remainder back into view, we will remember to tolerate the imperfection that distinguishes humanity, to affirm the existence of ambiguities in ethics as much as in biology. Recognizing—and valuing—this variability, the “problem” of intersex can no longer make sense as a problem. Atypical sex anatomy is not some exceptional difference, but an ordinary matter of our humanity. Like most human matters, it is not clean, or tidy, or easy, but it is a vital measure of the embodied vulnerability we are obligated to protect. Acknowledging the value of our imperfection lays the groundwork for the ongoing reflection that is the condition of our flourishing.

Notes

Introduction

1. The issue of “incidence” of atypical sex has been a vexed one, as it concerns not only the frequency with which children are born with atypical sex anatramics but also what counts as atypical sex. Early discussions of the varying estimates and questions they raise may be found in Dreger 1998b, 40–44, and in Fausto-Sterling 2000, 51–54. More conservative estimates of 1 in 2,000 (Intersex Society of North America) or 1 in 4,500 (Hughes et al. 2006, 554) (an incidence comparable to cystic fibrosis) refer to cases where sex is unclear at birth. The estimate of 1.7 in 100 at which Fausto-Sterling’s team arrived—what she cautioned “should be taken as an order of magnitude estimate rather than a precise count” (2000, 51)—refers to overall incidence of birth in which sex anatomy differs from the norm. This number would include the high, and apparently increasing, incidence of hypospadias (where the urinary meatus that is typically located at the tip of the penis appears elsewhere in children who are usually regarded as unquestionably male) (Center for the Study and Treatment of Hypospadias 2013). Questions of “rarity” can serve to justify extraordinary care in pediatric conditions, including those concerned with atypical sex or gender identity (see, e.g., Feder 2007, 55–56).

2. Like Kessler’s article, Eve Kosofsky Sedgwick’s 1991 article “How to Bring Your Kids Up Gay” brought attention of the new diagnosis to those outside of psychology. As she points out, the inclusion of gender identity disorder coincided with the removal of the diagnosis of “homosexuality” from the Diagnostic and Statistical Manual of Mental Disorders.

3. I would elaborate on this point in Family Bonds (Feder 2007, 60–69).

4. McCumber published the book by that same title in 2001. He notes that philosophers were disproportionately targeted by the House Un-American Affairs Committee (HUAC), whose work began in 1949, and argues that the significant changes that occurred at this time shaped the discipline in ways that have gone unremarked upon in the field. “The McCarthy era,” McCumber contends, “imposed an important restriction on just what kind of goals philosophers can pursue. It limited them to the pursuit of true sentences (or propositions, or statements)” (2001, xvii–xix).

5. In his famous essay “How Medicine Saved Bioethics,” philosopher Stephen Toulmin makes a similar point about the dominant nature of ethical inquiry at this time. However, he argues that bioethics greatly enriched ethical inquiry precisely by bringing “cases,” the individual “situation,” to the fore. He writes admiringly of the contribution made in the 1950s by Joseph Fletcher, who introduced the phrase “situation ethics.” But as Toulmin points out, “Fletcher’s use of the term met with harsh criticism” (1982, 740). While Toulmin argues for seeing the ways that bioethics enriched the field of ethical inquiry in philosophy, bioethics itself, as Hilde Lindemann (2006a) has provocatively put it, continues to occupy a “feminized”—that is to say, devalued—position within the discipline of philosophy.

6. Hannah Arendt was one of the notable exceptions to this regard, but less the rich contemporary engagement with her work lead us to forget. Arendt was herself the target of scorn by American philosophers even in the late 1970s. McCumber recounts in his book how members of the APA working on an accreditation committee for the state of New York described Arendt as “an unproductive drone because her works were not cited in important journals such
as the *Journal of Philosophy* and *Philosophical Review*. Of course, she published regularly in the *New York Review of Books* (no obscure venue), had been on the cover of *Time* magazine, and was one of the most famous political thinkers in the world (McCumber 2001, 51–52).


8. President Clinton issued the first apology to the government in 1997, addressing the eight remaining survivors and the descendants of the subjects of the study.

9. *The Belmont Report* (1979) was commissioned by Congress to "identify the ethical principles which should underlie the conduct of biomedical and behavioral research with human subjects and develop guidelines that should be followed in such research." The report was the product of the congressional commission formed after the passage of the National Research Act of 1974. The act was prompted by congressional hearings convened after the revelation of the infamous Public Health Service study of untreated syphilis in African American men from 1932 to 1972 and mandated that federally funded research be subject to Institutional Review Board (IRB) approval. According to Jonsen, some guidelines already existed, namely, those produced by the Nuremberg Code (1947) and the Declaration of Helsinki (1964) (see Jonsen 1998, 102). Tellingly, not a single member of the commission was trained as a philosopher, though two of its members held doctoral degrees from departments of religion, thus illustrating the longer history of a claim that philosopher Jorge Gracia made in 1998: "Philosophy has no place in public life. There are no discussions of public policy that include philosophy. Philosophers are generally excluded from policy-making bodies or posts in which they can have serious influence on the development of public policy" (quoted in McCumber 2001, 93).

10. As if it were possible to have an even dimmer view of the existing problems and future prospects for bioethics, in recent years Carl Elliott has sounded an alarm about the state of bioethics. He sees in the shortcomings of bioethics a worrisome problem in medicine that he attributes to the "studied indifference to deeper moral questions" (1999b, 7). In this climate, clinical ethics, he writes, "has increasingly become part of the bureaucratic structures whose problems it was intended to correct" (12). Indeed, Laura Stark's recent account of the development of IRB review in *Behind Closed Doors: IRBs and the Making of Ethical Research* suggests that this indifference became entrenched a decade before *The Belmont Report* and continues still. She describes the efforts beginning in the 1960s of NIH leaders whose development of human subject review committees was intended "to avoid getting sued, while also protecting researchers' scientific freedom and continuing to be well funded with taxpayer money" (2012, 198). Stark's account suggests that IRBs were intended and continue to function for the purpose of protecting the institution from liability rather than as a means to safeguard the human rights of the subjects of their research.

11. I would learn directly from Katrina Karkazis, who was at this time beginning work on her dissertation in anthropology, that she was watching the angry exchange provoked by my request with great interest and that, learning from my mistakes, she had better success in soliciting research subjects for the work that would become *Fixing Sex* (2008).

12. Most of these interviews were conducted by phone or via Skype, but some were conducted in person. With the permission of all participants, I recorded these conversations and transcribed them using pseudonyms—the names of trees—and eliminated the locations of the physicians and hospitals in order to protect the identities of any patients who had been in their care.

13. As I discuss in chapter 1, it is clear that a greater number of individuals with atypical sex anatomy became "medicalized" in the late nineteenth century. With the increasing number of specialists in this area of medicine, it may be that the standards of "normal" anatomy have a wider reach, which is to say that more children with atypical sex anatomy are medicalized today even than they were twenty or thirty years ago. But in the absence of anything more than anecdotal evidence, which would be very hard to come by, it is not possible to substantiate this hypothesis.

14. That is not to say that intracultural conflict is absent. See, e.g., the essays in Paren and Asch 2000.

1. The Trouble with Intersex

1. In the 2012 meetings of both the American Association of Clinical Endocrinologists and the Endocrine Society, there was no discussion or substantial call for training of endocrinologists in the management of CAH in adults. Only a handful of specialists have detailed knowledge of adult care for individuals with CAH. I thank Richard Aucutt, professor and fellowship program director in the Division of Metabolism, Endocrinology, and Diabetes at the University of Michigan, for his help in clarifying the current state of care for adults.

2. While it was distinctive, it was not unique in this respect. Hermaphroditism shared the dual status of medical curiosity and social threat during this period with other "ills" such as prostitution (see, e.g., Walkowitz 1982) and "racial difference" (see, e.g., Gilman 1930).

3. It is unfortunate that there remain so many gaps in the historical studies that could provide more insight about these developments and the continuities (and discontinuities) between and among them. Dreger's history ends with the work of the Briton William Blair Bell, whose work appears to mark the beginning of what we might call "the age of gender." Blair Bell's contribution resonates powerfully with salient features of the standard of care evident still. As Dreger writes: "If men and women were to be kept distinct, Blair Bell realized, hermaphroditism would have to be accomplished in such a way as to quiet sex anomalies, not accentuate them" (1999b, 166; emphasis added). The ongoing legacy from the Age of Gonads, however, is the insistence that each body be understood as having "a single true sex, and the medical doctor would be the determiner or creator of it" (168).

One can imagine a thread connecting the work of Blair Bell in England to that of Wilkins in the United States. Eder's work is particularly significant in addressing the gap between the end of the mid-twentieth century and the work of John Money and his colleagues in the United States four decades later, but there is a good deal to fill in between the two. There are also no systematic studies of the late nineteenth-century treatment of hermaphroditism in the United States. From Elizabeth Reis's study we may gather that physicians in the States relied upon influential work by British and French physicians (e.g., Arthur Evans and Charles-Marie Debierre) (Reis 2009, 86). More detailed investigation would be particularly illuminating to better understand the significance of the ways that US work in the mid-twentieth century may have radically reversed the geographical flow of influence in the field of medicine, or perhaps especially in this particular field. Understanding, too, the extent to which the treatment of "hermaphroditism" on both sides of the Atlantic mirrored the treatment of other kinds of conditions that provoked social anxiety might also provide further insight into the ways that the medical management of atypical sex was characteristic of medical treatment of its time.

4. The exception may be found in the work of the French surgeon Jean Samuel Pozzi, who was responsible for the "therapeutically important observation that undescended testicles in male pseudohermaphrodites often become cancerous" (Dreger 1999b, 64–69).

5. See also Michel Foucault 2003 [1999], 315–318.
4. Von der Pforrden's analysis of the appearance of the term "dignity" in the third formulation of the categorical imperative and not the second formula (of the "end-in-itself") substantiates O'Neill's contention that autonomy is not a property of individuals (see Von der Pforrden 2009, 377).

5. The Southbury Training School is a facility for children and adults with cognitive impairments. There is no indication in the film that Heinemann is cognitively impaired, and the film does not remark on the fact that his residency could have been damaging not only because he had no contact with his family but also because, at the very least, the education he would have received there would not have been appropriate for a child with typically developing cognitive capacity.

6. Even in those cases when the deployment of a given technology would appear to make one stand apart, specifically to become abnormal (the case of apotemnophilia, "the attraction to the idea of being an amputee" [Elliott 2009, 209] being the most notorious), the desire to fit in, Elliott argues, plays a central role.

7. Pediatric specialist Walter Miller makes this point with regard to the prenatal administration of demeclocycline, a steroid intended to reduce the masculinization of genitalia in 46,XX females with congenital adrenal hyperplasia. In correspondence with Alice Dreger, he wrote, "It seems to me that the main point of prenatal therapy is to allay parental anxiety. In that construct, one must question the ethics of using the fetus as a reagent to treat the parent, especially when the risks are non-trivial" (see Dreger 2010a). Following the authors of the Consensus Statement, it seems to me that we could make exactly the same observation about many of the practices associated with normalizing atypical sex.

Conclusion

1. For readers who are physicians and medical students, I will add that it should be clear that the ancient philosophical "care of the self" to which Foucault refers is far more encompassing and demanding notion that shares little with the increasing emphasis on "self-care" that medical schools have integrated into their curricula. These latter are more concerned that medical students attend to getting enough sleep and exercise to manage the stress and anxiety associated with the demanding nature of a medical education (see, e.g., Kushner, Kessler, and McGaghie 2011).

2. On the other hand, any parent who has survived toddlerhood knows—because she has learned—in the words of a parent I admire, that "the easy way is not the easy way": giving in to the tyrannical child with desires to be disruptive or disrespectful or refuse healthy food or watch more TV, and so on, is an invitation to more of the same.

3. In 2012 Lisa I. Lezoni and her colleagues from the Mongan Institute for Health Policy at Massachusetts General Hospital published findings from a 2009 survey that indicated a disturbing, if unsurprising, admission by a large proportion of the nearly two thousand practitioners surveyed: physicians do not always tell their patients the truth, disclose what many would consider conflicts of interests (e.g., financial ties to a pharmaceutical company), or provide full information about a disease, prognosis, or medical error (see Lezoni et al. 2012; see also the article appearing in the New York Times reporting on the survey [Chen 2012]). But the fact that the avoidance of " paternalism" is one of the fundamental principles of bioethics suggests that its routine violation has long been recognized.

4. Because the sex of assignment is generally not in question in cases of children with hypospadias, there has been some dispute over its inclusion as an "intersex" condition. This dispute may be owing to urologists' resistance to seeing the standard of care for hypospadias as a part of the standard pertaining to the normalization of other DSD—that is, other conditions involving atypical sex anatomy—that have been subjected to far less thorough testing. The phenomenon certainly is more common than other DSD: the Center for the Study and Treatment of Hypospadias at the University of California—San Francisco describes it as "one of the most common congenital anomalies," and it is reported to occur in 1 in 250–300 births. Moreover, its incidence has increased substantially, as reported in Europe and in the United States (Center for the Study and Treatment of Hypospadias 2013). But because hypospadias is regarded as the result of an incomplete development of the penis, its inclusion as a "disorder of sex development," or DSD, seems nonetheless appropriate.

5. Indeed, intersex activists beginning with Cheryl Chase have claimed that if there is something like "an intersex identity," it is the product of a medical treatment. In its effort to normalize the bodies of those with atypical sex anatomy, this treatment has itself "fixed"—that is, produced—the stigmatic difference these interventions are meant to conceal. Argentine activist and scholar Mauro Cabral made this same point in his testimony before the Inter-American Commission on Human Rights in Washington, D.C., in March 2013.

6. A search of PubMed, the U.S. National Library of Medicine index of biomedical literature, yields multiple citations for the term "hypospadias cripple" through 2012.

7. The Swiss report was immediately available in English, but as of this writing the German report has not been translated, though a summary was disseminated in a press release issued the day the opinion was published. I am indebted to Andrea Tschemplik for her assistance with and translation of the German text.