INTRODUCTION

It is the evening of May 17, 2000, and I am seated in a packed auditorium at the New York Gay and Lesbian Center on Little West Twelfth Street in Manhattan for the presentation of the Felipa de Souza Award. The prize, given by the International Gay and Lesbian Human Rights Commission (IGLHRC), is awarded to individuals and organizations that have made significant contributions toward securing human rights and freedom for sexual minorities. Tonight, Cheryl Chase, the founder of the Intersex Society of North America (ISNA), is being honored for her efforts to change the medical treatment for people with intersex diagnoses, work she began in earnest in 1993. The audience is standing room only, filled with human rights and gay activists, intersex adults and their supporters, a world renowned specialist on intersexuality, and John Colapinto, who had just published his book *As Nature Made Him: The Boy Who Was Raised as a Girl.* The book, about the tragic story of David Reimer, whose penis was burned off during a circumcision accident and who was subsequently raised as a girl, would hit the *New York Times* bestseller list several months later. Although Reimer did not have an intersex condition, he was treated by the psychologist John Money, the man largely responsible for developing the current treatment paradigm for intersexuality, making Reimer's heartbreaking story important for intersex activists fighting to change medical care.

The executive director of IGLHRC, Surina Khan, excitedly introduces Chase, noting that before ISNA, "very few of us knew about intersexuality." Arguing that there is no justification for early genital surgery other than "doctors' quest for normalcy," she likens the procedures to torture, calling it intersex genital mutilation. "This is wrong. It's torture. These children are subjected to involuntary surgery. Intersex people are not sick, they are not in need of care, but so-called rational medicine is coming after these kids with knives in their hands." The audience responds with a huge round of applause.

Although I am deeply sympathetic to intersex adults' criticisms of their medical care, Khan's comments paint a disturbing image of half-crazed doctors running down hospital corridors wielding knives—one that clashes with my knowledge of clinicians working in the field of intersexuality, whose intentions are more benevolent. I wonder what the clinical specialist in the audience makes of the claim that he and his colleagues are mutilating children. I furtively glance over to gauge his response; his face is expressionless, unreadable. It is hard not to get caught up in the heartfelt emotion of the moment and to be excited by the radical rethinking of intersexuality implied by the director's critique: Why are gender-atypical bodies construed as a medical problem? Should the medical profession have the right to make treatment decisions at all for people born with intersex conditions? But it is equally hard to believe that the issue is as simple as doctors torturing children. I am brought back to the moment by a huge round of applause as Chase takes the stage.

Chase tells a deeply moving story about her parents' experience at her birth. She explains that when she was born her mother knew something was wrong with her baby; and that doctors sedated her mother for three days while they figured out what to tell her. Eventually the doctors told her parents that they had a "deformed boy" and sent them on their way. At age one and a half, Chase's parents took her to be evaluated by specialists who concluded that their son was actually a girl with a large clitoris. As she tells it tonight, "the doctors decided to remove my clitoris, told my family to leave town and not tell anyone what had happened, and to destroy all the old photos of me as a boy," recommendations that sent a loud message that their daughter's condition was shameful and something to be hidden at all costs. "They felt that by doing this I would become a well-adjusted girl, marry a man, and have children," Chase says with a wry smile, adding: "Well, their prediction did not work out." The last point elicits uproarious laughter—Chase is a lesbian—and then she pointedly adds, "They picked the wrong person to do this to."

Although her language and demeanor is more tempered, Chase's analysis of what is problematic about the treatment of intersexuality is not far removed from Khan's. Doctors, she argues, do not understand female sexuality, think homosexuality is a failure of treatment, refuse to refer families to therapists and social workers, and encourage parents never to discuss the diagnosis with others or the child, thus instilling extraordinary shame in parents (and hence the child) about the condition. Focused on normalizing infants, she notes, doctors have failed to ask what intersex individuals themselves want. Early genital surgery, she says, is intersex genital mutilation,

and "the number of people targeted is one in two thousand or five a day," recasting what doctors understand as medical treatment as, instead, a gender battle waged on the bodies of small children.

Fast forward to October 2005 when fifty international experts in such fields as pediatric endocrinology, pediatric urology, genetics, and gender-identity development are gathered in Chicago to revise treatment guidelines for infants born with what are broadly called intersex diagnoses.[1] It is the first time researchers and clinicians will so thoroughly revisit the medical standard of care for these diagnoses since Money and his associates first proposed treatment standards in the 1950s. Chase and another patient advocate have also been invited to participate, a kind of collaboration unimaginable a few years earlier. The meeting would not have happened without intersex activists' growing chorus of demands, beginning in the early 1990s, for changes in medical treatment practices that had driven the field into a deep and divisive crisis by the year 2000.

The earliest challenges to the traditional treatment paradigm came from a number of adults who had been treated as children and who felt that this treatment paradigm, with its focus on rapid gender assignment and genital surgery, had caused extraordinary and irrevocable harm, even though it had been designed to ease their psychological and social adjustment. They pointed to the lack of complete and honest disclosure to parents about the child's anatomy and condition and to the child about her or his treatment history, to the rush to normalize atypical genitals by performing surgery, and to the desire to erase gender atypicality in the name of care. In addition, some of these individuals have asked why bodies challenging traditional beliefs about gender difference have been construed as problematic and forced to conform to male and female ideals through hormonal and surgical shoehorns (Fausto-Sterling 1993). While doctors decided how to deal with bodies that transgressed naturalized ideas about gender difference, intersex activists and others argued that it was the rigid ideas of gender difference that were transgressing the nature of their bodies.

At the Chicago meeting, participants agree to recommend several important changes to care that demonstrate a significant shift in thinking. Providing recognition and advising caution, the guidelines state that intersex conditions are not shameful and suggest that psychological care should be integral to medical treatment. Given that patients and parents (and even clinicians) often find the terminology and labels surrounding intersex diagnoses confusing, misleading, stigmatizing, and distressing, participants agree to change the medical nomenclature. In the proposed system, the term

intersex would be replaced by the more general descriptor "disorders of sex development" (DSD), referring to congenital conditions in which chromosomal, gonadal, or anatomical sex development is atypical. Other terms such as *hermaphroditism*, *sex reversal*, and gender-based diagnostic labels were to be replaced by a system based on clinically descriptive terms (e.g., *androgen insensitivity syndrome*).[2]

Suggesting a willingness to think more expansively about culture-bound assumptions about gender and its relationship to sexuality, the guidelines note that homosexuality should not be construed as an indication of incorrect gender assignment, a point that Chase had made five years earlier at an annual meeting of pediatric endocrinologists, the specialists primarily responsible for treating children with DSD. Participants also recommend that the potential for fertility—originally emphasized for female gender assignment only—be an important consideration for male gender assignment as well.

Despite the unquestionably positive developments they encompass, the guidelines also encapsulate the more entrenched obstacles to medical understandings of and treatment practices for intersexuality. From the standpoint of treatment, the new guidelines fail to resolve an issue that lies at the center of current controversies—early genital surgery. The guidelines acknowledge that there are minimal systematic outcome data about genital surgery, that orgasmic capability may be harmed or even destroyed by such surgery, and that there is little documentation to support the widely held belief that early surgery relieves parental distress about atypical genitals. The statement nevertheless says that surgery can be considered for young girls with "severe" genital virilization, which would include procedures to reduce a "too-large" clitoris or to create, open, or elongate a vagina on babies and toddlers.[3]

Although the guidelines incorporate important changes based on intersex adults' and others' criticisms of care and will foster increased awareness of these criticisms among physicians, they demonstrate an unwillingness (or inability) to think about intersexuality in terms other than biomedical (and pathological). From the physician's point of view, gender assignment or surgical techniques are controversial, but the existence of intersex bodies and the need to treat them are not. From a medical standpoint, what is at issue in debates over intersexuality is not the category intersex per se, but what theories and technologies are most appropriate to treat individuals with intersex diagnoses. It is rare for clinicians to view the line separating intersex from non-intersex as culturally determined because most physicians

see their taxonomies as apart from culture, not as reproducing culture (Kessler 1998). But the whole reason intersex even exists as a category is because these bodies violate *cultural* rules about gender. These rules assume an agreement among a series of somatic characteristics (chromosomes, gonads, genitals, and secondary sex characteristics) and more phenomenological processes such as gender identity, gender role, and sexuality. The debates over when to perform surgery and how best to decide gender assignment obscures the fact that in trying to make infants with intersex diagnoses "normal" boys and girls, physicians and parents are necessarily drawing on cultural ideas about what constitutes male and female.

By avoiding these broader questions and issues, including whether gender atypical bodies require treatment, the guidelines sustain the assumptions that physicians should intervene in embodied processes to control the "sex" of the body, that treatment might be a wholly unambiguous good, and that good intentions result in good care. These assumptions stem from the fact that biomedicine, characterized by pragmatic thinking and preoccupied with materiality and physicality, often atomizes or individualizes issues and pinpoints the body and its parts as appropriate sites of intervention. Science and medicine normalize the view that adjusting the material world to human aspirations is a positive goal (Rapp 1999).

My reason for lingering on these guidelines is not because I (or anyone else) expected them to solve all aspects of these debates once and for all, but because they illustrate that questions still linger of exactly which aspects of intersexuality are open to questioning, who belongs "inside" to evaluate medicoscientific problems, and to what extent they are allowed to participate (Harding 1991). Perhaps unsurprisingly, given their narrow, medicalized view of intersexuality, the guidelines fail to address the widespread social fears and assumptions that drive responses to intersexuality: namely, a vision of gender fraught with overdetermined investments, desires, and anxieties that creates the need for consistent and unified gendered ways of looking and being. From this perspective, the guidelines appear as little more than a new biomedical technology for the management of intersexuality (see Rapp 1999: 45).

Far from existing outside culture, biomedicine is a cultural entity that not only has unparalleled discursive and practical powers to define and determine what it is to be normatively human but also to withstand alternative constructions and challenges to its version of normativity (Rapp 1999: 13–14). Indeed, the guidelines assume that what constitutes normal bodies and ways of being is uncontested, unambiguously understood, and that the im-

pact of treatment might be universally assessed. They also embody the presumptive universality of terms and phrases such as *good sexual function*, as if this were self-evident, understood and experienced similarly by all persons. The guidelines are consistent with assumptions that biomedical experts alone can and should judge what would constitute a "good" outcome to treatment. They provide a sealed and self-confident narrative of the important issues in the treatment of intersexuality.

Eschewing any wider social and cultural context for understanding intersexuality, the guidelines instead enclose it in a discourse of medical management. Their vocabulary is predominately medical, with no language available to frame alternative descriptions or understandings. Nor does the document provide much critique of the assumptions that drive treatment. The lack of sustained attention to gender as a way of marking difference, or to how ideas about gender variance are rooted in our cultural practices of thinking about the body, circumscribes how we understand intersexuality and what we, as a society, believe should be done for those born with gender-atypical anatomies. Human sexual difference is seemingly obvious and certainly real on many levels, but in another sense it is a carefully crafted story about the social relations of a particular historical time and place, mapped onto available bodies (Fausto-Sterling 1995: 21).

Nevertheless, the meeting itself and the gradual shift in recommendations would not have happened without a decade of efforts to change medical protocol by intersex adults who felt harmed by their treatment. The inclusion of ISNA in particular marked a shift in the aims and the reputation of a group that began as a collection of outsiders toward whom clinicians felt deep suspicion and antagonism; instead, it now emerged as a (limited) partner and resource for ideas about how to improve care. Early activism attempted to make intersexuality visible and to convince clinicians of existing problems with the standard of care. A decade later, the topic has received extensive coverage in documentaries, newspapers, magazines, on television, and even in novels.

At birth, the sex of every infant is determined based on an inspection of the external genitalia and the understanding of the newborn as a "girl" or a "boy." The process of gender assignment at birth is usually uneventful, but each day, somewhere in the United States, an infant is born for whom gender assignment is not obvious. These infants may have any one of numerous diagnoses,[4] but their common feature is gender-atypical anatomy—a combination of what are typically considered male and female chromo-

somal, gonadal, and genital characteristics—which is often signaled by the presence of what clinicians call ambiguous genitalia.

Prior to the middle of the twentieth century, medical intervention in intersexuality was not routine in the United States and in some cases occurred only in adolescence or adulthood at the request of the individual.[5] Although physicians had long been assigning gender at birth based on the predominant characteristics of the external genitalia, and medicine at this time was developing increasing authority in matters of the body and thus of sex determination, its involvement in theses cases was ad hoc. This is in part because medicine had little to offer in terms of treatment, successful or otherwise. By the middle of the twentieth century, however, intersex births had come to be labeled a medical and social emergency.[6] Raising a child with a gender-atypical anatomy (read as gender ambiguity) is almost universally seen as untenable in North America: anguished parents and physicians have considered it essential to assign the infant definitively as male or female and to minimize any discordance between somatic traits and gender assignment. Since the 1950s, clinicians have used a treatment protocol developed by John Money and his colleagues at Johns Hopkins University to assign a gender. Emphasizing thorough but swift clinical workups to determine the etiology, clinicians determine a sex for these infants, and surgeons then modify the infant's body, especially the genitals, to conform to the assigned sex.

The shift to interventionist treatments for intersexuality resulted from developments in areas such as plastic surgery, urology, biology, and endocrinology. The most important development, however, was the work on gender identity by Money and his associates. Gender identity and role, they argued, was not something individuals were born with, but something built up cumulatively over time, much as the acquisition of a language. It was also malleable to a certain extent: Money suggested a small window of gender flexibility (until eighteen months of age) before which gender should be assigned. These authors stressed the importance of thorough assessments of infants born with so-called ambiguous genitalia to identify the etiology, assess the intervention possibilities, and determine the intervention most congruent with anticipated physical developments in puberty and adulthood. This treatment model was quickly and broadly adopted.

For roughly four decades, Money's recommended treatment was widely accepted by clinicians and virtually unchallenged by those treated. This situation changed dramatically in the 1990s. As some children treated according to the protocol reached adulthood, they began reexamining what had

happened to them. Traumatized and angry, they started to look for sources of information about their situation and for people who had undergone similar experiences. The rapid expansion of the Internet, with the development of relatively confidential, anonymous online discussion forums, facilitated these efforts. Simply finding ways to live with the consequences of their diagnoses and treatments did not satisfy some affected individuals; they have instead sought to change the context in which intersexuality is understood and treated to, they hope, save others from experiencing similar pain and distress.

Drawing energy from social movements for women's rights, civil rights, and gay liberation and building on recent challenges to and shifts in medical authority, intersex adults and their supporters have increasingly claimed knowledge and authority about the meaning and appropriate medical response to intersexuality. On one level, those in the intersex advocacy movement have variously objected to the timing and necessity of genital surgeries, to the biomedical notion that genitals are naturally dimorphic, and to the presumption of heterosexuality implicit in the treatment recommendations. Some have also questioned the right of the medical profession to make treatment decisions at all. On another level, this movement has argued for the acceptance, dignity, and humane treatment for those with gender-atypical bodies in an effort to challenge ideology, practices, and consciousness.

These developments emerged in a context of broader social changes in attitudes toward the body, gender, and sexuality, and toward the authority of science and medicine. At about the same time, feminist academics, parents of children with intersex diagnoses, and eventually clinicians, ethicists, and legal scholars began offering alternative views on the meaning and construction of intersexuality and appropriate medical responses to it. These views provoked turbulent controversies in the popular media, propelling intersexuality from the shadows to popular consciousness. What was once known only to physicians, researchers, and those affected suddenly became showcased in national newspapers and on network television programs. In academia, intersexuality emerged as a staple in many women's studies courses for what it revealed about the social construction of gender.

What made these criticisms possible and perhaps even inevitable? The naming and treating of intersexuality represents one aspect of the increasing tendency to turn social issues into biomedical problems that can be solved by clinical intervention. The current treatment protocol provides a structure and a method for addressing violations of gender rules that individualize, privatize, and depoliticize the meaning of those transgressions. In this view, gen-

der problems exist within the body of the individual, not in social and medical understandings of what is gender-typical or even healthy. Intersex is a catchall category that encompasses dozens of medical diagnoses, but the defining feature is that intersex bodies in some way violate the commonly understood biological differences between males and females. Intersexuality does not represent a point of pure liminality between sexes. The category intersex relies on the very categories of the medicalization of sex, and it is meant to cover a range of disparate diagnoses and biologically diverse individuals. But the breadth of human physical variance is more complex than the category allows for.

Bodies, Medicine, and Gender

Although this book explores a seemingly exotic or rare issue, intersex is unique only because it makes explicit the cultural rules of gender. Put another way, because the treatment for intersexuality exemplifies attempts to codify normality and abnormality, the frequency of intersexuality is less important than ideas about how to make these infants "normal" boys or girls. As clinicians and parents try to make sense of a situation in which the expected bodily concordances have not occurred, they are forced to answer complicated questions: Can a girl have XY chromosomes? Are some penises too small for a male gender assignment? The controversies about the adequacy and consequences of these decisions bring into sharp focus mainstream cultural rules about the proper relationships among bodies, gender, and sexuality that apply to all persons and raise fundamental questions about all bodies by forcing a reassessment of what is understood as natural and normal in connection with the human body (Lindenbaum and Lock 1993: xi). What bodily parts, experiences, and capabilities are necessary for an individual to feel he or she is a man or a woman? And, ultimately, how are bodies, gender, and genitals involved in the creation of men and women? The discussions about whether and how to treat intersexuality expose our cultural anxieties about sex, gender, and their relationship to sexual desire and behavior.

I eavesdrop on these discussions and debates in relatively unguarded moments, when doctors and parents discuss what to do about infants with gender atypical bodies. Their opinions about what constitutes a good outcome reveal the underlying logic of how different bodily parts and functions (e.g., chromosomes, gonads, external genitals, and intercourse) and ways of being normally go together, and what different cultural logics can be used to bring about the supposedly next best outcome.

Bodies whose appearance departs from social and cultural expectations are often subject to various forms of medicoscientific disciplining. Surgical normalization has been one method of reconfiguring such "deviant" bodies. Although surgery can sometimes ameliorate otherwise unsustainable lives—as in some cases of cleft palate—such procedures performed with the intention of normalizing the body often fail to offer that which is hoped for or promised. Whether cast as corrective, reconstructive, or cosmetic, such a surgical reshaping of atypically embodied persons has the effect of limiting human variation and expressing a disdain for atypical bodies. Intersex embodiments are congenital variations that are disabling not so much in that they present functional limitations—which all embodiment does to one degree or another—but rather in that they are corporeal configurations that violate cultural standards. Bodies occupy terrain at the boundary between self and society; they are both subject and object. As a consequence, they are highly politicized and have played significant roles in social crises. Biomedical knowledge and practices have proven instrumental in regulating bodies and populations through their ability to delve deeper into the body, producing highly technical knowledge, facts, concepts, taxonomies, and categories. Medicine has established itself as the sole decoder of the body's many signs. Indeed, medicine has become a dominant discourse in all aspects of life—birth, growth, death, health, and sexuality. Biomedicine's cultural and material authority—the source of its power—is constantly produced and reproduced, creating a cycle critical to its continued existence. But its power, as this book will show, is not fixed or all encompassing.

Difference in the body has long been used as the basis for supporting social projects (Terry and Urla 1995). The body becomes a primary way to locate and mark difference because of its materiality; its realness as it were makes difference appear concrete and unassailable. Situating differences in the body through scientific endeavors reinforces their natural status. The body, far from being a self-evident organic whole, is at best a nominal construct and phantasmatic space imagined very differently over time and across various cultural contexts (Martin 1987). The understanding, knowledge, and representation of the body constitute means to structure complex social relations and establish flows of power. One central articulation of bodily difference is gender. Gender difference has been assumed to extend not simply to the social but to all aspects of the body and biology, and both aspects are assumed to stand in fixed relationship to one another.

Until recently, intersexuality was framed exclusively in medical terms, in large part because over a century ago biomedicine assumed authority over its

classification and treatment. The privileging of biomedical understandings has naturalized categories such as those of normal males and females—and their corollary, supposedly abnormal males and females—at the expense of exploring how these understandings are produced and reproduced. Whatever intersexuality may be physiologically (and it is many things), intersexuality as a category of person (requiring medical treatment) is not natural (Holmes 2002). That is, although all bodies are natural in the broadest sense, medicine's formulation of some as intersex is not natural, creating instead a category accomplished in culturally distinctive ways.

Indeed, the power of medicine and science lies in their ability to define what is natural, to name nature and human nature, and in their claim or hope to return individuals to a more natural state or way of being. Medicine and science are grounded in the taken-for-granted status accorded to biological "facts." The distinction between nature and culture relies on a model of nature that is eminently cultural—that is, on a specific concept of the natural that can stand for itself as a domain of immutable and fixed properties. Fierce debate about what the category of natural comprises, as well as about how society deals with that which does not fit into the concepts of the natural or normal, hardly seems surprising. The demarcations of some bodies, behaviors, and ways of being as normatively gendered—and others as not—is a biopolitical project that raises fundamental questions about how to understand the role of medicine in shaping and governing humans and human experience (Adams and Pigg 2005).

Sex, Gender, and Sexuality

The categorization of individuals as male or female is woven into the fabric of daily life, often in ways that elude our awareness. Cultural understandings of categories such as male and female and ideas about appropriately gendered subjects drive treatment decisions for intersexuality. Male-female gender dichotomies permeate discussions of intersex at numerous levels—from debates over where sexual difference is located in the body, and which organs or genitals properly sexed subjects can or should have, to the sexual orientation and sexual behavior of appropriately gendered subjects. This book examines debates over intersexuality for what they reveal about cultural understandings of gender difference. It exists on numerous levels: anatomical difference (males and females), behavioral and psychological difference (masculine and feminine behavior and gender identity), and erotic difference (masculine and feminine sexuality).

Prior to the 1970s many took for granted that biological sex determined one's identity and behavior. Unlike sex, a biological concept, gender was imagined as a social construct specifying the socially and culturally prescribed roles that men and women should follow; it either grew out of biology or was mapped onto it. Several sequelae derive from this distinction. First, biology and culture are constructed as distinct realms. Second, biology is assumed as stable, immutable, and internally consistent for males and females. Third, biology is the substance on which culture works, rather than the other way around.

In the 1970s feminists theorized a distinction between biological sex and gender, highlighting that reproduction did not cause gender difference in any natural or obvious way (Rubin 1975: 159). Arguing that the relationship between the two is far from natural but instead a system by which sex is fashioned into gender, they sought to weaken biological essentialist arguments that ascribed women's inferior status to innate biological differences. In this early work, the material body remained essentially male or female; it was the system of gendered social behaviors attached to these bodies that was open to critique.

In this critique the sex-gender system not only required identification with one sex but sexual desire also was directed toward the other sex (Rubin 1975: 122). Although sexuality and gender are interwoven in complex and varying ways, and cultures tend to experience these linkages as natural and seamless, the specific configurations and points of connection vary historically and across cultures (Vance 1991). Cultures in modernity have assumed an intimate connection between being male or female—a distinction based on a set of physical organs, traits, and characteristics, as well as on reproductive capacities—and the "correct" form of erotic behavior, namely, penile-vaginal intercourse between a man and a woman (Weeks 1986: 13). The construct of difference between males and females and the belief that reproduction is the natural and desired outcome of sexual activity undergird this view.

Our insistence on a so-called true sex is tied to a deep and abiding social interest that individuals engage in "correct" (i.e., socially sanctioned) forms of sexual behavior (Foucault 1980). This *moral* interest in limiting licentious behavior (largely, but certainly not exclusively, focused on same-sex behaviors) has driven the social interest in the *medical* determination of a single true sex. The assumed concordance among bodies, gender, and sexuality provides an ideological framework for the treatment of intersexuality. Clini-

cians and parents aim to provide a gendered picture that they recognize as cohesive and consistent, in turn producing norm-abiding gendered subjects.

In a theoretical move that represented a departure from other feminist theory of the time and that still resonates today, scholars sought to dismantle two particularly pernicious and taken-for-granted beliefs: that only two genders are given in nature and that sex exists as a biological fact independent of time and place (Kessler and McKenna 1978). Dichotomous gender, far from being natural or innate, or based in our being, is accomplished, constructed, and reproduced in interactions and interpretive processes. Most radically, this critique asserts that the biological is as much a construction as the social; through an understanding of the social construction of gender, biological sex becomes completely destabilized as a separate and coherent category. From this perspective there is little need to distinguish between gender-dichotomous characteristics defined as biological (e.g., chromosomes) and all other aspects of the male-female dichotomy (McKenna and Kessler 2000). When the word *gender* is used to include what we commonly understand as sex (i.e., biological differences), female and male are no more objective or real than the socially constructed categories of woman and man. What was thought to be the base or root of gender difference is actually an *effect* of gender (Kessler and McKenna 1978; Butler 1990; Laqueur 1990; Kessler 1998).

Despite more than twenty years of thinking on this subject both within and outside academe, these formulations have largely not taken hold. We often do not treat the category of gender as problematic, do not view biology as constructed, and even continue to believe that our genitals make us who we are (McKenna and Kessler 2000: 70). Researchers in many disciplines have learned, and continue to teach, that whereas gender is cultural, sex is biological. For those who have grown accustomed to this conceptual distinction, the case for sex itself as a social construction remains to be made.

In this book, I draw heavily on Kessler and McKenna's formulation and on Kessler's later work on intersexuality that derives so beautifully from her earlier work with McKenna. Following their lead I ask, if one postulates bodies (including genitals, gonads, chromosomes, and hormones), what more does the word *sex* buy us? By saying that sex is really about gender, however, I run the risk of failing to problematize the body as a culturally formed dimension, suggesting that the body has no significance in the process of gender construction or minimizing the body as a material fact. The body as a material fact is given, but sex is not. By exploring the interweaving among gender's constructions and its embodiment and lived expe-

rience, I hope to show how the lens of gender literally shapes the body, and what this means for individuals who undergo treatment procedures and interventions for intersexuality.

It has been said that feminist academics concern themselves more often with meaning than with flesh or real people (Tuana 1996). To say this is not to diminish the importance of meaning but rather to argue that it is inadequate by itself. We need to understand and interrogate what these meanings imply for lived experience. In the same way that bodies are co-constituted by biological and cultural concepts, they are also both theoretical and lived. Intersexuality raises interesting theoretical questions, but it is not only a theoretical question.

Current clashes over taxonomies and treatments of intersexuality are not merely questions of semantics. Because intersex management rests on cultural understandings of masculinity, femininity, sexuality, and the body, the very process of defining these categories and their relationships has significant consequences not only for those directly involved (children, parents, and doctors) but also for larger contemporary debates about how to understand these relationships. Debates over intersexuality raise basic questions about how bodies, gender, and genitals are involved in the creation of men and women. Consequently, any redrawing of the boundaries of intersex has tremendous potential to redefine how we understand commonsense categories such as male and female.

Intersex, then, is a core location at which, to borrow a phrase from Andrew Lakoff and Stephen Collier (2004: 427), "how to live is at stake"—a location both made problematic and resolved by a binary and discrete conceptualization of gender as a primary alignment, as a regime of living that guides medical practice and holds binary gender together. With so much at stake, the intensity of the debates comes as no small wonder.

Methods

Research on intersexuality from other than biomedical perspectives is relatively recent and constitutes a small, though growing, body of work. Scholars working in disciplines such as history, sociology, social psychology, philosophy, and comparative literature have made important contributions to understandings of intersexuality in a historical and cultural context (Foucault 1980; Epstein 1990; Fausto-Sterling 1993, 2000; Daston and Park 1995; Dreger 1998a, 1999; Kenen 1998; Kessler 1998; Hausman 2000; Feder 2002; Holmes 2002; Hester 2003, 2004; Preves 2003, 2004; Redick 2004). Much of

this work is excellent. My aim is not to provide a corrective to these other accounts, but to build on and extend them by closely examining contemporary controversies.

This building on and extending of previous work largely results from my methodology, which I turn to shortly, and from the fact that I conducted my research at a high point in the controversies. The medical management of intersexuality has moved into scholarly and public consciousness in an unprecedented and significant way over the past decade. Much of the previous social scientific work on intersexuality has tended to focus on one group of actors (e.g., clinicians or intersex adults), to utilize one methodology (e.g., textual analysis), or to address one time period (usually prior to the current debates). A large portion of the previous analytical work has looked exclusively to texts (Foucault 1980; Epstein 1990; Fausto-Sterling 1993, 2000; Daston and Park 1995; Dreger 1998a; Kenen 1998; Hausman 2000; Hester 2003, 2004; Redick 2004). Fausto-Sterling, for example, provided important conceptual ideas about the medical perspective on intersexuality, much of which were based on her close readings of the medical literature (1993, 2000).

Textual analysis, however, cannot tell us how clinicians conceive of their work, interpret theories and guidelines, and make decisions. Interviews with clinicians, a rich source of data, have remained largely unexplored since Kessler conducted her groundbreaking interviews with six clinicians in 1985. Drawing on these interviews, and using gender as a primary analytical frame, Kessler provided a cogent and still resonant analysis of how clinicians think about treatment for intersexuality (Kessler 1990). My interviews with clinicians extend those by Kessler by interviewing a larger, contemporary sample of clinicians *after* intersex activism and the ensuing controversies began. This enabled me to ask pointed questions about clinical decision making in the context of controversies as they were taking place, to explore how Money's paradigm is applied in clinical settings, and to examine areas of disagreement among clinicians. I was also able to examine how medical paradigms of intersexuality change in response to internal professional developments and challenges by nonexpert medical consumers and the public. How do clinicians react to internal and external challenges to the dominant medical paradigm? Do practices change in response to these criticisms and, if so, in what ways?

Clearly the views of those individuals treated by clinicians provide another important perspective, as do the views of parents. Preves, the first to interview intersex adults about their treatment experiences, examined how indi-

viduals cope with the stigma of being labeled as gender deviant, arguing that the medical intervention into intersexuality often creates, rather than mitigates, this stigma (Preves 2003). Feder conducted interviews with parents about their experiences during the same period I did, arguing that medicine has not only failed to examine parents' experiences but that parents' feelings of confusion and isolation are built into the treatment processes themselves: often they receive neither full information abut the child's condition nor referral to psychosocial resources (Feder 2002).

Both Preves and Feder have provided rich analyses of the viewpoints and experiences of individuals with intersex diagnoses and their parents. Where my work departs from theirs is in the range of subject matter covered in the interviews and in my triangulation of both viewpoints with that of clinicians. This triangulation afforded me the opportunity to contrast the main conceptualizations of intersexuality for the participants, as well as the explicit or implicit understandings of gender and sexuality among the three groups. It also allowed me to ask: Who has the authority to determine what constitutes a good result in medical treatment? What are the legitimate boundaries of medical intervention, especially regarding treatments meant to address social, rather than medical, difficulties? What constitutes good data in evaluating outcomes—like sexual function, pleasure, or satisfaction with treatment—that are always subjective?

Building on this work, my aim was to capture, clarify, and contextualize the current controversies over a treatment protocol and treatment practices that have dominated intersexuality care since the 1950s. Despite heated debates, scarcely any data are available on the practices of treatment for intersexuality. How do physicians arrive at a gender assignment for an infant? Although the typical wisdom is that gender assignment is largely based on phallus size, my work shows that medical decision making proves much more complex and contradictory. Phallic length matters, but so, too, do chromosomes and hormones. We do not know why parents may choose surgery or not, what factors contribute to these decisions, and how they ultimately feel about their choices. What fears and hopes shape surgical decision making?

The lack of data about medical treatment for intersexuality has serious consequences. Without some understanding of what is actually happening and why, physicians, parents, and others cannot thoroughly evaluate current practices and devise ways to improve treatment. Without these data, questions will remain about treatment practices, treatment's efficacy, and the long-term impact on the children who are treated. My hope is thus to provide

a snapshot of the current treatment practices for intersexuality in the United States and, more important, to explore the rationale behind it.

As with any such study, it is important that the reader understand how I came to know what I claim to know (Rapp 1999: 11). I employed a range of ethnographic methods, including participant observation and semistructured open-ended interviews, to investigate the spheres of activity under scrutiny here. I supplemented this ethnographic work with primary and secondary literature research in post–World War II reproductive science, biomedical ethics, U.S. political theory, and feminist and other writing on intersexuality itself. I also researched media accounts of controversies about intersex, starting with the earliest protests at medical conferences.

Often one hears of going to the field in anthropological studies. For this study, the field encompasses hospitals, Web sites, conferences, family discussions, protests, the *Oprah Winfrey Show,* and *Dateline*—anywhere discussions, negotiations, and contestations of intersexuality take place. Although debates about intersexuality have exploded into so many venues in the United States that it would be impossible to trace all of the discussions, I attempt to trace and present a broad array of voices.

I use several methodologies to assess the varied and often competing understandings of intersexuality. Those involved—primarily clinicians and researchers, parents, and intersex adults—interact in varied and complicated ways, often neither directly nor publicly. I followed the actors to the loci of these discussions using a wide-ranging, itinerant approach aimed at tracing connections (Heath et al. 1999: 452).

My data include over fifty-three in-depth interviews with clinicians and researchers, intersex adults, and the parents of children with intersex conditions, most of which were conducted from 2000 through 2002.[7] I did the majority of these interviews in person; however, when costs made face-to-face interviews prohibitive, I conducted interviews over the phone. Interviews lasted one to four hours each, with clinician interviews often being the shortest and those with adults with intersex conditions the longest. The length of the interviews depended on the time available to the person, the rapport we developed, and the interviewees' willingness to share their experiences and thoughts.

I interviewed nineteen clinicians or researchers of various specialties who treat intersex conditions: eight surgeons (either pediatric urologists or pediatric surgeons), nine pediatric endocrinologists, one child psychiatrist, and one research psychologist. Many of these clinicians are leaders in their field. I identified them through reading the medical literature on intersexuality and following the debates, as well as through consultation with medical in-

siders, participant observation at professional meetings, and recommendations by other clinicians. I tried to capture a range of opinions by interviewing clinicians with different specialties, years in practice, and geographic locales of training and practice. I sought to interview a gender-diverse group of clinicians; however, men dominate the surgical fields that treat intersexuality and outnumber women in the other specialties. The youngest clinician I interviewed had been in practice one year; the most experienced clinician had more than twenty years of clinical experience treating intersexuality. Finally, I sought out clinicians trained at diverse institutions who are now practicing at hospitals serving varied populations. Of course, given the relatively short period in which pediatric urology and endocrinology have been specialties and the rather narrow opportunities for apprenticeship, diversity was more of an ideal than a reality.

In addition to the clinicians, I interviewed fifteen intersex adults and fifteen parents of children with intersex diagnoses. Before explaining how I selected these individuals, I want to say a word about terminology. The term *intersex* is used by all clinicians, but not by all parents or affected persons. Part of the debate concerns precisely what conditions or types of body count as intersex. Some people consider the label *intersex* as central to their sense of self; for others it holds no personal relevance, and yet others see it as incorrect and even deeply offensive (see chapter 8). My aim is not to serve as an advocate or detractor for any particular term but to note that much is at stake in contestations over terminology. That this issue is debated so fiercely highlights the importance of the power to name things and to self-identify. Few terms define the boundaries of this varied and diverse group. Although some, as I noted earlier, have recently begun using the phrase *disorders of sex development* (DSD) in an effort to lessen the stigma tied to *intersex*, my sense is that this term, though in some ways less culturally loaded than *intersex*, still leaves intersexuality fully medicalized and construes gender difference as a disorder requiring treatment—a position with which I do not agree. With reservations, then, I use the terms *intersex* and *persons with intersex conditions*.[8] I do not mean to impose a label or an identity that the individuals concerned do not employ. Moreover, I am deeply aware that this usage may privilege clinical interpretation and understanding over personal experience, or vice versa, and that terms such as *intersex person* emphasize intersexuality before personhood. It is an imperfect solution. I will later discuss the objections to this term raised by participants, which I hope will provide a context for the limits of its descriptive usefulness.

More important and problematical, the category *intersex* blurs as soon as

one attempts to draw its borders, and this uncertainty itself makes for a component of and a complication in the debates. Any assumptions about what conditions are intersex are refigured in conversations with clinicians, affected adults, and parents. Clinicians may refer to females with congenital adrenal hyperplasia (CAH), for example, as intersex; but many women with CAH do not consider themselves intersex, and some vehemently oppose the inclusion of CAH under the rubric of intersexuality. Parents also express varying levels of willingness to consider their child's diagnosis (and thus their child) as intersex. Had I interviewed only people who identified as intersex or who identified their children's condition as intersex, I would have missed an important and emotionally charged aspect of the current debates.

Studies of people with intersex diagnoses or their parents necessarily work with samples of convenience, rather than with sampling frames. There is no national census of individuals with intersex conditions to utilize, no directory, no registry. Consequently, I was concerned about what researchers call selection bias, particularly for a population that is partially hidden, lacks a consensus for membership, and is dealing with stigma. Indeed, disputes over representativeness frequently recur in these debates (see chapter 8). As a result, I was acutely aware of arguments already circulating; namely, that intersex activists were the "disgruntled minority" and that there was a silent and essentially happy majority from which the public did not hear because they were doing well. My sensitivity to these arguments led me to exercise great care selecting my sample.[9]

To capture the heterogeneity of adults with intersex diagnoses, it would have been inappropriate to employ only one method of recruiting participants in the study. To avoid capturing only activist perspectives, I purposely did not rely on ISNA to recruit my sample. Instead, I contacted numerous support groups for both adults with intersex diagnoses and for parents and visited Web sites geared toward affected adults and parents. Some may rightly argue that those belonging to groups somehow differ from those who do not (it is an empirical question whether they are better or worse off than those who do not participate). For this reason I also pursued referrals by clinicians, parents, and intersex adults (see below). As in any research, however, if someone does not agree to participate, it is hard to know how they are different, if at all, from those who did.[10]

I mostly limited myself to contact with individuals and groups oriented toward CAH and androgen insensitivity syndrome (AIS), or intersex diagnoses in general, for two reasons. First, CAH accounts for roughly 60 percent of all infants born with ambiguous genitalia, meaning there are simply

more individuals with this diagnosis (Grumbach and Conte 1998: 1360). Although AIS is not as prevalent, AIS support groups and resources are relatively well organized. A focus on these two diagnoses allowed me to trace common themes in the concerns, treatments, and lives of those with each diagnosis (and thus the variability between diagnoses) that might not have been possible had I only interviewed one or two people with each diagnosis. As a consequence, all of the adults I interviewed were women, save one man with partial AIS (PAIS) who was raised female and began living as a male in early adulthood. (Another woman with PAIS was raised male and began living as a woman in adulthood.) Also, the majority of genital surgeries that have sparked so much controversy are performed on individuals with these diagnoses, making these groups an important source of information.

Unquestionably that I interviewed only one person who identifies as male is a limitation of the present study. Yet I had little trouble locating adults with intersex diagnoses willing to be interviewed; many affected adults referred others to me. Parents are rightfully protective of their children, and concerns about how their children's condition may be represented often make them cautious and reserved; nonetheless, I also found more parents than I could interview. In three instances, adults I interviewed told their parents about my work, so that I later interviewed the parents as well. A number of clinicians I interviewed referred me to their patients, and a few individuals made efforts to contact me after hearing about this project.

My status as an outsider, though a caring one, made it possible for me to interview adults and parents with diverse backgrounds and treatment experiences. Although some were "out" to friends and others, a surprising number had never shared their stories with anyone. As an outsider, I was not the parent, primary caregiver, or clinical caregiver, and I had no vested interest in what they said. I think this status helped enormously in ensuring the honesty and integrity of my conversations.

I do not claim my data to be representative of the viewpoints or experiences of all individuals with intersex diagnoses and their parents. It bears repeating that this is not the aim of qualitative research. Nevertheless, my interviewees represented a broad cross-section of individuals who were diverse on numerous levels. Participants were located in more than twenty states; the intersex adults I spoke with ranged in age from twenty-one to fifty-five. The youngest parent I interviewed was twenty-four and the oldest fifty-nine. Their children ranged in age from five months to thirty-eight years.

The participants were also socioeconomically diverse, almost equally divided between the working and the middle class. More than half had com-

pleted college. All families except one had health insurance that covered the treatment of their children. Fewer than half of the participants identify as or are comfortable with the label *intersex* for themselves or (to a lesser extent) their children. Half object to the term and do not use it. Roughly half of the adults with intersex diagnoses that I interviewed have had same-sex sexual experiences; however, they do not necessarily identify as lesbian. Some were uncertain about their sexual orientation. Some have had multiple sexual partners; others have had none. Most have had genital surgery, but several have not. Most parents chose genital surgery for their infants, but some did not. Of those parents who chose surgery, some regretted the decision, while others did not.

I found some common themes striking. For example, adults with intersex diagnoses had similar experiences regarding clinical visits, genital exams, secrecy about their diagnosis and treatment, and shame about their bodies. Many parents spoke of very similar birth and treatment decision-making experiences. In addition, some of the arguments for performing early genital surgery, for example, are frequently echoed by both parents and clinicians. In contrast, arguments for not performing genital surgery were similar among women who have had genital surgery, irrespective of other demographic characteristics.

The current book is not an outcome study in the clinical sense. Nevertheless, I think it offers valuable insights into the treatment experiences of adults and parents. In clinical outcome studies, clinical viewpoints can be privileged. I hope that giving a voice to affected persons and parents may redress this imbalance to some degree.

In addition to conducting interviews, I undertook participant observation at a wide variety of public venues discussing intersexuality. To capture the clinical perspective, I attended (and still do) numerous medical meetings, grand rounds, conferences, and other professional medical meetings. Several clinicians facilitated my access to closed medical meetings. They also provided contacts to other clinicians and patients and informed me of new developments. I attended annual meetings of key medical associations (e.g., of the Lawson Wilkins Pediatric Endocrine Society, the Midwest Pediatric Endocrine Society, the Society for Pediatric Urology, the American Urological Association, and the American Academy of Pediatrics), smaller medical lectures and meetings (e.g., the John Duckett Urology Lectures), grand rounds at numerous teaching hospitals, and meetings of the North American Task Force on Intersexuality (NATFI), as well as some of the meetings of NATFI's Research Protocol Working Group.

To capture the perspective of affected adults and parents, I observed support group meetings, activist fundraisers, everyday operations at ISNA offices, patient-led grand rounds, intersex human rights awards, many of the meetings of the San Francisco Human Rights Commission, and other functions. I have also tried to keep abreast of the many Web sites and discussion groups for specific diagnoses, parent support groups, meetings, and newsletters.

Finally, I have been immersed in this issue since 1997, when I first began exploring the topic. Much of my time since then has been spent engaged in some aspect of intersexuality. So, in addition to what might be described as formal research, I have spent many hours in informal discussions with other clinicians, parents, and intersex adults whom I did not formally interview but whose perspectives are central to my overall picture of the debates under discussion here. More recently, I have begun giving grand rounds on the topic and presenting my work to diverse audiences, both clinical and nonclinical. My research sites are essentially unbounded, which adds both to the pleasure and the difficulty of ethnographic research.

Despite my attempt to capture the depth and breadth of experience, this study is limited in several important ways. Because I was interested in clinical decision making and parent-clinician interaction, I would have preferred to observe actual clinical encounters at the birth of an infant with an intersex diagnosis. Unfortunately, because of the sensitivity of this issue, and the nature of multisited research, such observations were fraught with difficulties. To compensate for this obvious limitation, I probed repeatedly for specific and detailed instances of clinical problem solving and parents' recollections of this period. Although I strove for racial and economic diversity among those I interviewed, my sample is overwhelmingly white, with only one African American adult. Because of my relatively small sample sizes, my ability to provide in-depth analyses of how understandings, decisions, and experiences are shaped by ethnoracial, class, and socioeconomic factors remains quite circumscribed. Finally, as noted earlier, I interviewed only one individual who identified as male.

Types and Frequency of Intersex Diagnoses

There are few reliable estimates of the frequency of intersexuality, in part because even the question of what diagnoses should count as intersex remains disputed and controversial. Estimating the frequency of intersexuality would require reconciling what somatic characteristics are strictly male or

strictly female (a task made impossible because few, if any, physical characteristics are exclusive to one sex) and which deviations from this norm count as intersexuality. How small a penis or how large a clitoris count as sexually ambiguous? Does one count sex-chromosome anomalies as intersex in the absence of any apparent external sexual ambiguity? Even with these questions settled it would remain extraordinarily difficult to determine population-based statistics for intersex diagnoses. In the United States, there is no national census or method for keeping track of intersex conditions.

Despite these difficulties, a few studies have attempted to derive estimates of the frequency of intersex diagnoses.[11] In a meta-analysis using data culled from international studies, the authors conclude that the frequency of all causes of "non-dimorphic sexual development" may account for 1.7 percent of all live births and that roughly the same percentage of the population may undergo genital surgery (Blackless et al. 2000: 159). Elsewhere, one of the authors writes that those who undergo genital surgery may be between one in one thousand and one in two thousand live births (see Fausto-Sterling 2000). Both statistics have been widely repeated in the lay press, as well as in academic and scientific articles.

Some believe these statistics are overinclusive, including infants with diagnoses that many would not consider intersex. One critic, Leonard Sax, argues that the common definition of intersex as any "individual who deviates from the Platonic ideal of physical dimorphism at the chromosomal, genital, gonadal, or hormonal levels" (Blackless et al. 2000: 161) is too broad and includes, as its own authors acknowledge, individuals who present no symptoms or outward signs at birth (Sax 2002). He argues for a more "clinically focused" definition restricted to conditions in which the phenotype (outward, physical characteristics) is not classifiable as either male or female, or in which the chromosomal type (e.g., 46,XX) is inconsistent with phenotype. According to Sax, the problem with the estimate by Blackless et al. is that individuals with the five most common diagnoses (late-onset CAH, vaginal agenesis, Klinefelter and Turner syndromes, and other non-XX and non-XY karyotypes) are very rarely born with ambiguous genitalia and should not be considered intersex. Sax counters that only about two in every ten thousand infants are born with atypical genitals (Sax 2002).[12]

The most common intersex diagnosis is CAH, an inherited condition affecting the adrenal glands.[13] The most common form of CAH is 21-hydroxylase deficiency, which has varying degrees of severity. Classical CAH, the most severe form, is typically detected at or soon after birth, and it occurs in approximately one in fifteen thousand births. Nonclassical CAH (NCAH), the

milder form, which may cause symptoms at any time from infancy through adulthood, is much more common than classical CAH and affects somewhere between one in one hundred to one in one thousand in the general population. The wide range is due to its higher frequency in some ethnic groups, such as those of Ashkenazi Jewish background.

A well-respected clinician and researcher argues that of the total estimate of 1.7 intersex births per 100 live births, 87 percent are due to the inclusion of individuals with late-onset or nonclassical CAH, who are not born with atypical genitalia, and also of infants with diagnoses such as Klinefelter and Turner syndromes, who are very rarely born with atypical genitalia. He argues that if one deducts these three diagnoses, the rate drops to one in one thousand live births, still based on very shaky estimates (Heino Meyer-Bahlburg, personal communication, April 12, 2002).

The second most common intersex-related diagnosis, AIS, occurs in individuals with a 46,XY karyotype. People with AIS have a functioning Y chromosome (and therefore no female-typical internal organs), but a mutation on the X chromosome renders the body's tissues (including genitals) completely or partially insensitive to the androgens the body produces. Depending on the degree of residual sensitivity to androgens, AIS will either be complete (CAIS) or partial (PAIS). In a fetus with an XY karyotype who does not have AIS, the genitals masculinize under the influence of androgens. In the case of CAIS, the external genitalia take a female form, whereas in PAIS, the appearance of the external genitalia ranges along a spectrum from male typical to female typical. Because AIS is a condition that affects androgen receptors, individuals have testes with the normal production of testosterone and a conversion to dihydrotestosterone, but the body cannot use the androgens the testes produce, and thus genital development is redirected. Another hormone produced by the fetal testes suppresses the development of female internal organs: thus individuals with AIS do not have fallopian tubes, a uterus, or an upper vagina. Data on the frequency of AIS in the United States are not currently available; however, the best available estimates suggest an AIS incidence of approximately 1 case per 20,400 infants with 46,XY karyotype.[14]

For many intersex diagnoses, prenatal diagnosis is rare either because it is not possible or not indicated. (If testing is possible it is often not done unless there is a family history of the condition.)[15] One route to prenatal diagnosis is fetal imaging. An ultrasound may occasionally reveal genital and gonadal atypicalities, but it cannot determine whether a fetus is likely to have an intersex diagnosis.[16] Amniocentesis, the sampling and analysis of

amniotic fluid usually performed between the fifteenth and twentieth week of pregnancy, allows for a prenatal diagnosis of nearly all chromosomal atypicalities (but not all genetic ones). Because it carries a small risk of miscarriage (roughly one in two hundred), as well as the risk of nonfatal physical damage to the fetus, it is usually offered only to pregnant women with an elevated risk of chromosomal or genetic birth conditions.[17] Risk factors include maternal age and a previous child or pregnancy with a birth defect. The lateness of the test makes any decision on keeping the fetus fraught with difficulties and has ethical charges as women are put in the position of judging the quality of their fetuses and thus the standards for entry into the human community (Rapp 1999: 3).

At present, even if they are aware of an elevated risk of a child having such a condition, parents and clinicians have only limited and imperfect options for prenatal intervention. If CAH is known to run in a family, the mother may be treated with dexamethasone (DEX), a powerful steroid. It replaces the cortisol the fetus with CAH does not produce, thereby reducing the production of excess androgen by the fetal adrenal glands, with the hope of reducing genital masculinization in affected female fetuses. For this therapy to arrest virilization, it must be administered throughout the pregnancy, starting early in the first trimester.[18] At this stage, however, many women may not know that they are pregnant, much less the karyotype (or genotype) of their fetus. Moreover, the treatment itself may complicate diagnosis. Prenatal diagnosis of CAH due to 21-hydroxylase deficiency by amniocentesis is not possible if DEX has been administered because it suppresses the levels of the steroid that are measured for diagnosis. To use amniotic fluid for prenatal diagnosis, the woman must discontinue DEX for about a week prior to the amniocentesis. Clinicians have more recently turned to genetic tests to determine the diagnosis as a way to avoid this interruption.

This steroid also has a number of undesirable side effects for the mother, and the long-term safety of the treatment on the fetus remains uncertain. Because, statistically, only one in eight fetuses will be an affected female if both parents are known carriers, seven of eight pregnancies may be treated unnecessarily. As a result, treatment with DEX is hotly debated. Clinicians therefore recommend accurate genetic testing to minimize unnecessary treatment.

Yet because of the current limitations of prenatal testing, the birth of a child with an intersex condition typically comes as a complete surprise to first-time parents and their clinicians. This may change dramatically in the coming decade as genetic testing is refined and streamlined. With the pos-

sibility of cheap and easy early-detection home pregnancy tests and minimally invasive prenatal genetic testing as a routinized standard of prenatal care, some have conjectured that fetuses with intersex diagnoses will increasingly be aborted.

Overview

I have divided this book into three parts. Part 1 begins with a chapter discussing the history of understandings of and the treatment for intersexuality, examining the complex technological and social developments that shaped and transformed it. Chapter 2 traces the development of the traditional treatment paradigm starting in the 1950s, while chapter 3 introduces the contemporary controversies.

Part 2 marks the beginning of the ethnographic portions of the book and explores contemporary medical treatment practices and decision making. In chapter 4 I explore how clinicians and parents locate sex when the typical markers of sex are absent or ambiguous. This discussion necessarily examines the factors clinicians think important for the development of gender identity. Debates about intersexuality reveal normative ideas not only about gender but also about sexuality. In chapter 5, I examine how beliefs about supposedly normal masculine and feminine sexual desires and behaviors figure into gender assignment and surgical treatment decisions made by parents and clinicians for intersex infants. Numerous assumptions about sexuality and its relationship to gender are embedded in and drive treatment practices for intersexuality, including the belief that heterosexuality is the natural sexuality and thus the correct sexual outcome for these infants, and that penile-vaginal intercourse functions as the exclusive heterosexual sexual act. As a result, genital surgery seeks to produce genitals that not only match the sex of the infant but that also enable or preclude certain sexual acts and thus certain ways of being.

Intersexuality combines scientific and technical practice with lived experience. Despite temptations to privilege either clinical authority and technology or the experiences of adults with intersex diagnoses, I endeavor to show how these aspects are tightly and crucially intertwined. I am interested in how clinicians, as pragmatic thinkers, individualize social issues, how they both constitute and transform gender, and how their ideas about gender influence their treatment decisions. When I question these decisions, my aim is not to deny the relevance of somatic traits or of the material markers and signifiers of sex, nor to make light of what individuals and families

experience or of clinicians' compassionate urge to use medical knowledge and skill to help them. Nor do I aim to portray medicine as a batch of bad intentions fueled by a desire to control people. Medicine is more benevolent than that, and its authority and power more diffuse. It is also certainly not solely responsible for the ways in which sex and gender are socially constructed. At the same time, after hearing of the lasting physical pain and psychological trauma of a number of those who have undergone genital surgery and other aspects of treatment, I find it impossible to absolve medicine of all responsibility, no matter how seemingly beneficent, well-intentioned, or sincere the clinicians' desire to help. Rather, my hope is to challenge what some understand as intersexuality in frameworks other than biomedical and to force some submerged questions to the surface: Why label some people as intersex? Whom or what does this serve and why?

I hope it is clear that I care greatly about those with intersex diagnoses and their families, about the difficult decisions parents face, and about the more difficult consequences of some of those decisions. These issues are explored in part 3, which represents my attempt to move away from clinical decision making to view the effects of medications, surgeries, and treatment decisions on the lived experience of those involved. Chapter 6 explores the experiences of parents of children with intersex diagnoses, their experiences of raising their children, and their relationships with their adult children. Chapter 7 explores the experiences of individuals with intersex diagnoses in childhood and adulthood. Finally, chapter 8 looks at the personal and social consequences of contemporary intersex management protocols by examining the efforts of activist groups and their influence on the current practice of medicine.

Following anthropological convention, all names used in the text are pseudonyms. Most of the individuals I interviewed preferred to remain anonymous; some agreed to talk to me only on condition of anonymity. Two affected individuals desired to have their real names used, viewing anonymity as a form of continued stigmatization. I respect this view and agree with it in many ways; however, it presented a problem when deciding how best to honor the wishes of all those I interviewed. Finally, those individuals who wished to have their names used said they would not object to pseudonyms. In giving each one, I do not mean to further stigmatize these individuals or to distance the reader from the life experiences of those who participated. In the end, I hope that the participants' words will help create a culture in which individuals can reveal their condition without fear of stigma or rejection.