

Introduction

“You’re in the Monkey Cage with Me”

Summer in Chicago is a time for exploring the city, visiting Lake Michigan, enjoying great food, and debating the causes of the Cubs’ inability to win. However, in the summer of 2008, a group of more than one hundred visitors chose to stay in their run-of-the-mill conference hotel rather than discover what Chicago has to offer. Mostly white middle-class women, young and old, from around the country, they had come to the Windy City for the annual meeting of the Androgen Insensitivity Syndrome Support Group–USA (AISSG-USA).

Unlike most other national conferences, this one had no posters with its name decorating the hotel. Instead, the signs that led attendees to their registration site displayed a colorful orchid and the words “Women’s Support Group” in bold letters, followed by “Please do not disturb.” Curious hotel employees and guests found the meeting mysterious. One employee asked me, “Why are all of you needing support?” I shrugged my shoulders, not sure how to respond.

In fact, the ambiguity of the signs was appropriate to the purpose of the meeting, whose attendees were distinguished by the fact that the sex they were born with had been deemed biologically ambiguous by the medical profession. To put it another way, almost everyone at the meeting had been born with an intersex trait (or accompanied someone born with an intersex trait). In many instances, the result was physical bodies incongruent with sex chromosomes.¹ In the past, these individuals might have been considered hermaphrodites, a term that some—but not all—in the intersex community now consider derogatory. Terms less contentious today include *intersex*, *intersex traits*, *intersexuality*, and *intersexual*, which I will use throughout *Contesting Intersex*.

This book is about how *intersex* is defined, experienced, and contested in contemporary U.S. society.² I argue that medical profession-

als have replaced intersex language with disorder of sex development nomenclature, a linguistic move designed to reclaim their authority and jurisdiction over the intersex body. Ironically, this disorder of sex development (DSD) terminology was strategically introduced in 2005 by Cheryl Chase, a prominent intersex activist, and her allies, who had hoped the new nomenclature would improve medical care for those born with intersex traits.³ Instead, as I show here, DSD terminology has heightened tension within the intersex community. Some individuals born with intersex traits are embracing the new nomenclature; others resist it, citing the pathologization that underlies the term *disorder*; a few are indifferent to diagnostic labels and think individuals should use whatever term(s) they prefer.⁴ My hope is that *Contesting Intersex* will tease apart the tensions over terminology in the intersex community, while also showing how power resides in diagnostic labels.

Although *intersex* is itself a term whose meaning is contested, in general it is used to describe the state of being born with a combination of characteristics (e.g., genital, gonadal, and/or chromosomal) that are typically presumed to be exclusively male or female. People with androgen insensitivity syndrome (AIS), for example, have XY chromosomes and testes “but lack a key androgen receptor”⁵ that consequently prevents their bodies from responding during gestational development and beyond to the normal amounts of androgens (an umbrella term for testosterone) their testes produce. Depending upon how much androgen the receptor blocks, some AIS individuals have ambiguous external genitalia (usually a larger clitoris that resembles a small penis) with either internal or external testes, while others have an outwardly “normal”-looking vagina with a shortened vaginal canal, no uterus, and undescended testes. Swyer Syndrome, sometimes referred to as XY gonadal dysgenesis, is another example of an intersex trait. Like individuals with AIS, people with Swyer Syndrome have sex chromosomes that are inconsistent with their phenotype (external appearance). Swyer Syndrome is characterized by the presence of testes (usually internal), but unlike those with AIS, individuals with Swyer Syndrome usually have a uterus, though it is generally smaller than usual. People born with traits such as AIS or Swyer Syndrome are sometimes referred to as “intersex,” meaning they do not fall into the binary of “male” or “female.” According to the Intersex Society of North America (ISNA), there are approximately twenty different intersex traits.⁶

There is no simple medical explanation for the cause(s) of intersex, no agreement on what defines intersex, and no formal record of those born with such “abnormalities.”⁷ All of these lacks presumably contribute to the challenge of establishing the frequency of intersex. Still, estimates have been made, with the most-used figure suggesting 1 in 2,000 people is intersex,⁸ but because estimates drastically vary across publications,⁹ I’m uncomfortable offering my own estimate. What I do know, however, is that intersex people exist all around the world.

Estimates of intersex in the population did not matter to the conference attendees, who shared a unique medical history and had a strong connection with one another. They were there to support one another in healing from what, for many, has been a life full of medical lies, deception, and unnecessary surgical intervention. Yet if you had happened to stumble into that Chicago hotel that summer weekend, you would have had no idea of what had brought the attendees together. Without the “Women’s Support Group” signs, you might have imagined that you were interrupting a meeting of sorority sisters or a family reunion. A group official told me that one reason for the secrecy was to prevent any attendees from feeling uncomfortable or “freakish.” This was also why the support group’s public website did not name the conference location.

I found AISSG-USA through that very website, as I searched the Internet for information about *my* intersex “abnormality.” As a twenty-seven-year-old individual with complete androgen insensitivity syndrome (CAIS), I had met only one other intersex person, a friend from work who was as private about her diagnosis as I was about mine. I wanted to know more about intersex, and I started my search for information online. Although I did not know it at the time, in doing so I was employing what Nikolas Rose and Carlos Novas (2005) label digital biocitizenship. To Rose and Novas, digital biocitizenship connects one electronically to a specific community via, for example, a support group website or e-mail listserv.

I was diagnosed with CAIS around the age of thirteen. I was experiencing abdominal pains, and my mother thought I would soon begin menstruating, a rite of passage for women in my family, as in many other families. However, my period never came. The abdominal pain went away, but my mother was concerned enough to seek medical advice. I soon found myself in an endocrinologist’s office, wondering why

so many doctors were literally looking over—and within—my body. At the time, the doctors told me I had underdeveloped ovaries that had a very high risk of being cancerous and would need to be surgically removed before my eighteenth birthday. But the doctors were lying: The purported ovaries were actually undescended testes. Encouraged by medical providers, my parents went along with the lie, and when I was seventeen, I had surgery to remove the supposedly dangerous organs.

I would not see a doctor again, or discover that I had an intersex trait, until, at nineteen, I relocated to a new area far from my childhood medical providers, where I sought new doctors. As is customary, they requested that I bring my medical records with me to my appointment for a routine physical. When I finally got my hands on my surgical records, I read them in utter disbelief. That was my first encounter with the truth about my body and the medically unnecessary surgery I had undergone. At that time, it made me deeply uncomfortable to learn that I had XY chromosomes and testicular feminization syndrome—the label for my trait when I was initially diagnosed. I was in tears as I read what one gynecologist had written in my medical file: “After extensive discussion I feel pt [patient] needs surgery to have gonads removed. She is not aware of any chromosomal studies and most literature agrees it best she not be aware of the chromosome studies. She has been told she is missing her uterus, she does have a vagina. She has no tubes. She has been told she may have streaked ovaries and they should be removed because of the possibility of developing gonadal cancer” (personal medical records, November 26, 1997).

I was shocked and confused. Why had my medical providers and parents lied to me for so many years? I thought I’d had surgery because of a health risk.¹⁰ Was having an intersex trait that horrible? I remember thinking I must be a real freak if even my parents hadn’t been able to tell me the truth. I ran to the dumpster outside my building and threw my records away, not wanting to be reminded of the diagnosis or the surgery that couldn’t be undone.

Almost a decade later, I was finally emotionally ready to confront my medical past, and I requested another set of my records. I was exploring feminist theories and gender and sexuality scholarship in my sociology doctoral program, an incredibly empowering experience that positioned me to revisit my personal experience with sex, gender, and sexuality

binaries. Our assigned readings and thoughtful classroom discussions encouraged me to delve deeply into my medical history, first with close graduate school friends and faculty, eventually with anyone who cared to listen. Finally feeling liberated, I sought others like me, which is how I ended up at my first intersex support group conference, which happened to be in Chicago that year.

This project was born during that emotional weekend, which will forever mark my first involvement with the intersex community. Although I entered the weekend as an individual with an intersex trait looking for peers, by its end I was determined to pursue a sociological analysis of intersex in contemporary U.S. society. Despite my personal experience with intersex, I was initially concerned that I would have difficulty gaining access to a community that hasn't had the best experiences with researchers, notably psychologist John Money, whose work was discredited after the discovery of his falsified data and unethical research practices (see chapter 3).¹¹ I was wrong: AISSG-USA was incredibly supportive of my research, as was each of the other organizations I studied. It became clear during data collection that my personal experience with intersexuality provided an inroad into the field and community that would eventually become my second home (see Figure 1.1). In the fall of 2013, I was elected president of the AIS-DSD Support Group, the new name of AISSG-USA, which had just started to allow men with intersex traits to attend their annual meeting (clearly, a lot had changed since I'd attended my first meeting).

As a result of the access, support, and assistance I received in connecting with intersex community members, I was able to collect a tremendous amount of data in a relatively short time. During this period, I formed friendships throughout the intersex community, to which I am now permanently connected. For I am not only studying the intersex community, I'm in it. As Peggy, a fifty-six-year-old with an intersex trait, said to me, "I feel that you're going to be on my side. You're not like someone at the zoo saying, 'Well I'm a human being and I'm taking notes on the monkeys.' You're in the monkey cage with me."

Like that of many of my research participants, my experience with intersexuality has left me with some horrific physical and emotional scars. However, it has also become the core of my intellectual passion and academic commitment. On January 7, 2010, in the midst of my data collec-



Figure 1.1. A publicly available photo of individuals with intersex traits at the 2010 Annual Meeting of AISSG-USA. I am surrounded in this picture by a handful of AISSG-USA members who, like me, have an intersex trait. I am the one standing in the middle of the crowd wearing a dark button-down and glasses. Photo uploaded to Wikipedia by Ksaviano.

tion, I met fifty-three-year-old Cheryl Chase, who was instrumental in the rise of the intersex rights movement nearly two decades earlier. As we finished our emotionally intense interview, Chase wrote on a piece of paper, “Georgiann, Finish your PhD and change the world!” That note, along with a framed picture of the two of us, greets me every time I sit down at my desk. It is not just memorabilia from the field; it is symbolic of my commitment to *our* entire community, no matter how divided—over medical terminology and how best to advocate for change—we are today.

The remainder of this chapter introduces the theoretical and methodological underpinnings of my study. I begin with a discussion of gender structure theory, a framework I rely on to understand the complexities of intersex in contemporary U.S. society. I then turn to my efforts to develop trust with the community before collecting interview data, the process of participant recruitment, and an overview of my participants. I end this section by turning the methodological lens on myself. While I acknowledge that my insider/outsider status offered access and insight into the intersex community, I use the concept of the looking-glass self

to explain how I unintentionally altered my appearance throughout data collection to match how I *believed* I would be perceived by those I was studying, regardless of whether such perception was warranted. This raises the concern that researchers may self-police their gender presentation. Studying the intersex community, I have been able to combine my personal and professional interests in an attempt to understand the complexities of living outside sex, gender, and sexuality binaries. My hope is that this understanding will help to elucidate how those binaries constrain all of us, whatever our genitalia.

Applying Gender Structure Theory

Contesting Intersex builds on the short history of sociocultural studies of intersex. For example, in 2003, sociologist Sharon Preves published *Intersex and Identity*, wherein she argues that intersex people confront through a series of overlapping stages of identity formation the stigma of being differently bodied. Preves documents how intersex support groups provide a venue for intersex people to connect with one another, resulting in the identity-based intersex rights movement. Preves's work was groundbreaking, but subsequent events have turned it into social history. In 2008, medical anthropologist and bioethicist Katrina Karkazis introduced an impressive methodological approach to the study of intersex in her book *Fixing Sex*. She was the first scholar to bring together rigorously the perspectives of multiple stakeholders in the community: intersex people, their parents, and medical experts. Karkazis eloquently shows how the medicalization of intersex—and the ideologies of sex, gender, and sexuality that are at the core of that medicalization—perpetuate medical authority over the intersex body. Her focus on multiple stakeholders and ideology makes her work an important precursor to *Contesting Intersex*, which moves forward to focus on intersex after the formal introduction of DSD terminology. But my concerns also differ in two important theoretical ways. First, I consider how the social construction of diagnoses made it possible for *intersex* to be transformed into a *DSD*, and second, I ground my analysis of intersex in gender structure theory.

Intersex is a problem because it disrupts the traditional gender order. If our behaviors weren't constrained by gender, if opportunities weren't

filtered through gender, and if gender weren't tied to bodies and identities, it is doubtful that intersex would be as problematic throughout the world as it is today. Thus, I ground this study of intersex in gender theory, specifically in the idea that gender needs to be understood as a stratification system residing not only in individuals but also at the institutional and interactional levels of society (e.g., Butler 2004, 1993, [2006]1990; Martin 2004; Risman 2004, 1998; Ferree, Hess, and Lorber 1999; Lorber 1994; Connell 1987). To do so, I frame my analysis with sociologist Barbara Risman's gender structure theory (2004, 1998), which I find particularly useful because it can be adapted to integrate other theoretical insights, such as the ideas of sociologists Nikolas Rose (2007, 2001) and Carlos Novas (Rose and Novas 2005) about the simultaneously individualizing and collectivizing nature of biological citizenship, Annemarie Jutel's (2011, 2009) theoretical contribution about diagnoses, and philosopher Giorgio Agamben's (2005, 2000) account of state of exception.

Gender structure theory conceptualizes gender as “deeply embedded as a basis for stratification not just in our personalities, our cultural rules, or institutions but in all these, and in complicated ways” (Risman 2004, 433). The institutional dimension of gender structure dictates—through a variety of structural processes, including organizational practices and policies about behaviors (e.g., Giddens 1984)—a powerful conceptualization of gender that is tied to bodies. The individual level of gender structure is where the development of a gendered self emerges through the internalization of a male or female identity and its assigned personality attributes (e.g., Chodorow 1978). Within this individual level of gender structure, we come to see ourselves as male or female and masculine or feminine—as if doing so were that simple, achievable, and unchanging. Although we see one another's genitals only in very intimate settings, we constantly make assumptions about whether one is male or female on the basis of gendered clothing, mannerisms, and hairstyles. This is the interactional dimension of gender structure and it is where people “do gender”: a function of social psychology that involves categorization by sex, which triggers stereotypes and gender expectations that ultimately influence how a person is treated, approached, and expected to behave in social circumstances (West and Zimmerman 1987; see also Garfinkel 1967 and Goffman 1976, 1959). Each of the dimensions of gender structure shapes and is shaped by the others. For example, our internalization

of a gender identity occurs in relation to how the law defines us at the institutional level and how, at the interactional level, we are expected to present ourselves and are consequently perceived by others.

The explanation in *Contesting Intersex* of how *intersex* became a DSD pays specific attention to the consequences of meanings of intersex at the institutional, individual, and interactional levels. At the institutional level, I explore these questions: How does intersex activism disrupt medical authority? How does the medical establishment make sense of and approach intersex bodies? What are the current treatment protocols, and what do these protocols imply about the medical institution's power and control over bodies? At the individual level, I focus on how individuals make sense of their diagnosis and understand the new DSD nomenclature, asking: What benefits and what challenges arise for those who reject DSD terminology? How are these terminological preferences related to one's understanding of gender as either an essentialist characteristic of the body or a socially constructed phenomenon? At the interactional level, I ask: How do medical professionals present intersex to parents of newly diagnosed intersex children? Does the way in which intersex is presented to parents influence how they respond to medical recommendations? What happens when parents learn about intersex from the intersex community, specifically from intersex adults and from other similarly situated parents? How do parents feel about the new DSD nomenclature? All of these levels are essential to my analysis.

Trust Matters

My process of building relationships with key players in the intersex community began when I attended my first AISSG-USA meeting in the summer of 2008, before I started to conceptualize my research. I attended the meeting as an individual with complete androgen insensitivity syndrome, not a researcher. I participated in workshops, including an intensely emotional session in which we shared our most painful stories about intersexuality. I explained how I had been compelled to revisit my intersex diagnosis and tackle it head-on by reading in a doctoral seminar on feminist theory about intersexuality and intersex advocacy. I sat in the classroom thinking: *Where* is this intersex rights movement? My personal experience was so different from what I was reading that

my professional interest was piqued. I started reading scholarly work on intersexuality. With each new piece, I found greater liberation. I discovered I wasn't abnormal. As I shared my story, others listened with compassion. They smiled, passed tissues, and offered chocolate. During that private session, as I saw how intersex was still a source of shame, secrecy, and pain for so many in my new-found community, I realized that my sociological study of intersex was needed.

At my very first AISSG-USA meeting, I connected with organizational board members, intersex adults, parents of intersex children, and medical experts on intersexuality. Although I immediately started planning my study and received institutional review board approval in October 2008, I didn't conduct my first interview until the summer of 2009. I believed from early on that building a rapport with key participants was necessary to the research process—especially in this instance, where participants may have had problematic experiences with other researchers. I wanted them to know they could trust me and the broader research process. According to sociologists William Foote Whyte (1984) and Ann Oakley (1981), interview data is only as good as the trust present during the actual interview. More specifically, Whyte identifies rapport as the first concern of the interviewer. I would go further and argue that it is the most important part of an interview. Without rapport, why would participants want to share their information and knowledge with a researcher?

Having entered the community as an individual with an intersex trait, I was exposed to the contemporary struggles in unique ways. My access reached further than traditional participant ethnography, because my first experiences with the community were truly participatory. I started wearing my researcher hat only after my first AISSG-USA meeting. This unconventional inroad into the field allowed me to formulate questions directly from the most natural observations possible. In turn, my methodological approach relied on the trust afforded to me by my own lived experience with intersexuality.

Participant Recruitment

My original intent was to interview up to one hundred individuals affiliated with the intersex community—or to conduct interviews up to the

point where I was no longer collecting new information, which is commonly referred to as saturation. I selected participants based on current or past involvement with ISNA, AISSG-USA, Organisation Intersex International (OII), and Accord Alliance. I chose these four organizations because their websites suggested that they were involved in intersex advocacy in different ways. In chapter 2, I discuss each organization's origins and development, including its goals and mobilization strategies. Here, I focus on the participants I interviewed, including intersex people, parents of intersex children, medical experts on intersex, and organizational board members.

I had no trouble recruiting participants for my study. When word got around that I was a researcher who had an intersex trait, I was contacted by many individuals who not only were willing to be interviewed but who also expressed a sincere desire to participate. Because ISNA, AISSG-USA, OII, and Accord Alliance are organizations with activism components, I anticipated that some participants would be eager to discuss their activism and organizational affiliations, and indeed they were. I also had little difficulty recruiting medical professionals who self-identify as experts on intersex. Many of the medical professionals I invited to participate agreed to do so on the basis of reciprocity. Medical professionals routinely ask individuals with bodies like mine to participate in their research studies, and, as one doctor politely put it when at an intersex support group meeting I handed her an invitation to participate in my research, "I'm always asking you people to help me, so of course I will help you."

In total, I interviewed 65 individuals, including 36 adults with intersex traits; 17 parents of children with such traits; 10 medical experts on intersex,¹² including surgeons, urologists, endocrinologists, and mental health professionals; and 2 social movement organizational board members who are not medical professionals, do not have an intersex trait, and are not the parents of an intersex child. (Appendix A includes a list of participant pseudonyms and select demographic characteristics.) Interviews ranged from 25 minutes to well over three hours. I traveled all over the United States to conduct interviews face-to-face in order to gain participants' trust and establish a level of comfort possible only in person. Participants chose the interview locations, which ranged from a semi-private area in a hotel during a support group meeting to homes

and workplaces. I also conducted several interviews in public spaces such as coffee houses and bagel shops and one in a rental car. I supplemented my interview data with more than 300 hours of ethnographic observations of people interacting in the public spaces of intersex organizational meetings. These observations also helped guide participant interviews.

To protect confidentiality, at the start of each interview I asked all participants who weren't medical professionals to choose a pseudonym. In some instances, participants elected to use their real first names, and I honored such requests. I assigned medical professionals random alphabet letters beginning with "A." Because very few U.S. medical professionals are experts on intersex, I have provided very limited demographic information about each of these participants. I obtained informed consent before I turned on the recording device at the start of every interview. All interviews were transcribed and coded using ATLAS.ti, after which I deleted and destroyed all audio files.

The majority of my participants with intersex traits identified as college-educated middle-class women, and about a third identified themselves as heterosexual or straight, while many of the rest identified as lesbian, gay, homosexual, bisexual, queer, or asexual. All of the parents of intersex children whom I interviewed identified as heterosexual, and most presented as women. The majority of medical professionals who appear in this study also identified as heterosexual, with slightly more than half presenting as women. The organizational board members I interviewed who did not have a personal connection to intersex identified as straight and presented as women.

Most of my participants had graduated from college, a pattern that calls for reflection. Given its biological origins, intersexuality clearly does not affect only those from more privileged backgrounds. Instead, it is likely that educated individuals have the cultural capital to seek out advocacy and support groups. Because my recruitment was limited to the four organizations identified above, it was difficult to locate participants who did not have a formal higher education. Steve, a fifty-five-year-old who hadn't finished high school, is one example. His daughter, a college-educated adult with an intersex trait, was connected to several intersex social movement organizations, and through her I was able to invite him and his ex-wife to participate in my project. When I interviewed Steve

over breakfast at an urban diner and asked if he felt connected to the intersex community or to other parents of intersex children, he replied, “I don’t know about intersex communities. My daughter had this problem, and I want her healthy. I don’t know about intersex communities.”

When I asked Steve if he ever searched the Internet for information about intersexuality, he laughed and responded, “Honey, I ain’t got a computer. I’m a mechanic who knows about cars. She ain’t sick right now, ya know? If she got sick, I’d get some help right away.” Sarah, Steve’s ex-wife, a fifty-five-year-old high school graduate, had a similar response when we sat down to discuss her experience with intersex and, more specifically, whether she looked to the Internet for answers about the trait. She said, “I’m not stupid, but there ain’t any reason to go on the Internet.” When I asked if she used e-mail, she rolled her eyes, laughed, and responded, “No, I don’t have time to waste on that shit.” Neither Steve nor Sarah had the tools that would lead them to intersex organizations. They didn’t use the Internet, and they didn’t see the Internet as a source of useful information.

As Preves (2003) documents in her book, most intersex people discover the details of their traits on the websites of intersex organizations.¹³ This is how support groups gain new members, and it is also how intersex people connect with one another.¹⁴ Most of what we know about how intersex is experienced in U.S. society is rooted in research with individuals affiliated with intersex support groups, which means that much of our understanding of intersex is rooted in a middle-class framework. This raises significant questions: How has framing intersex as a middle-class condition biased our knowledge about the diagnosis? What can we learn about intersex from personal narratives outside of the middle class? While my sample did not allow me to address these questions, they must be acknowledged.

My research participants with intersex traits were, relatively speaking, racially and ethnically diverse. Approximately 30 percent were of a racial/ethnic minority status, but their experiences of intersexuality did not substantially differ from those of the white research participants. Given that the racial and ethnic minorities in my sample had completed at least some college and most held college degrees, it seems likely that the absence of racial/ethnic differences has more to do with common educational backgrounds than with any potential claim that racial and

ethnic minorities at large experience intersexuality in similar ways to white individuals. In other words, I'm suggesting that the cultural capital gained from educational attainment may explain, at least partially, the lack of any observed relationship between race/ethnicity and experience with intersexuality. This is, of course, another empirical question that is worthy of further investigation.

Most of my participants presented as men or women rather than say genderqueer, and my interactional classifications were consistent with how they referred to themselves.¹⁵ I found classifying their sexuality to be much more difficult. The sexuality I assumed, based on cues tied to gender presentation, didn't always match with a participant's self-reported sexuality. For example, several people I assumed were lesbian by how they dressed and/or wore their hair actually identified as heterosexual. This observation is not surprising, as we know we cannot, nor should we try to, predict one's sexual identity by one's gender presentation.

Insider/Outsider

I knew from the start that I would not study intersexuality for academic purposes exclusively. As an individual with an intersex trait, I am personally connected to the intersex community and advocacy movement whether I choose to be or not. I am thus committed to presenting a scholarly study of intersexuality from the perspective of an intersex feminist academic. As feminist intersex advocate Emi Koyama and interdisciplinary scholar Lisa Weasel documented in 2002, most of what we know about intersexuality is the work of academics and clinicians who do not have a personal connection to intersex; while such perspectives can provide valuable contributions, they do not make up the entire puzzle.

Since Koyama and Weasel's critique of intersex scholarship by non-intersex academics and clinicians, several academics with intersex traits have publicly written about intersex. In 2008, Morgan Holmes, a Canadian sociologist, drew on her personal experience with intersex in her compelling account of intersex adults and their struggles in a world that continues to construct sex and gender as natural binary characteristics. Holmes specifically problematizes intersex medical care by highlight-

ing the complicated relationships between binary ideologies about the body and biomedical power and authority. As an “inside informant,” she has produced work that is priceless (Holmes 2008, 64). For more than a decade, Iain Morland, a cultural critic in the United Kingdom, has published extensively on intersex, including his 2009 “scrutiny of intersex activism” wherein he examines the complexities “between activism’s critique of medicine and medical reform” (191). Cary Gabriel Costello, a sociologist at the University of Wisconsin–Milwaukee, has also written extensively about intersex from the perspective of an intersex person who has gender transitioned. He maintains two public blogs—The Intersex Roadshow¹⁶ and TransFusion¹⁷—on which he discusses an array of topics, from intersex fertility to sex/gender checkboxes that we are forced into on forms such as birth certificates.

Like Holmes, Morland, and Costello, among others, I integrate my personal experience and my professional analysis in *Contesting Intersex*. However, my specific goal is to understand how *intersex* became a controversial *DSD*. My unique insider/outsider access to the intersex community enabled me to collect data that might otherwise have remained unavailable to such a project. Individuals can hold an insider or outsider standpoint in every community; the production of scientific knowledge is best served by collecting perspectives from each and all of these standpoints.¹⁸ As much as we are all insiders within certain communities, we are also outsiders to different communities. I define *insider* in the research context as a researcher who has a personal and historical connection to the population or phenomenon being studied. My definition of *outsider* in the research context is a researcher who does not have a personal connection to the population or phenomenon being studied.

I occupied a unique insider/outsider status throughout most of this project. I was an insider in the sense that I was born with an intersex trait. My participants and I shared experiences of living with an intersex trait. However, when I began this project, I was not truly an insider, for I had no historical connection to the intersex community or even to any other individuals with intersex traits. In fact, it wasn’t until the 2007–8 academic year that I was fully aware an intersex community even existed. As a result, I define insider/outsider status in the research context as a researcher who has a personal connection with the phenomenon being studied but no historical connection.

My insider/outsider status proved to be incredibly useful not only in gaining access to the intersex community but also in the type of data I was able to gather. Because I am an intersex person, participants on all sides of the community expressed increased comfort in speaking with me. For example, Ann, a fifty-two-year-old with an intersex trait, said, “It made it more comfortable . . . it’s easier for me to talk to you.” Because I experienced living with intersex, I was personally familiar with many topics that surfaced in interviews, from terminology to difficulty of engaging in penetrative sex because of a shortened vaginal canal and/or vaginal dryness. Jenna, a thirty-one-year-old with an intersex trait, described how my personal familiarity made interviews go more smoothly: “I guess as far as ease of explanation [goes] it’s a little easier because you know the terminology. You know when I say TFS . . . you know I meant testicular feminization . . . and when I say AIS or I say gonadectomy or I say whatever . . . you know what I’m talking about. You know it, you have it.” My personal experience with intersexuality also made some people more willing to participate in my study. As Marty, a forty-three-year-old parent of a teenager with an intersex trait, put it: “You’ve experienced this . . . you have a connection . . . If you were just somebody, or if your child didn’t have it, or you didn’t have it, then I think I wouldn’t do this [*points to recorder*] . . . it’s like a sisterhood.” While many participants shared Marty’s view, others said they would have participated regardless of my personal experience with intersexuality.

Still, given my insider/outsider status, these individuals expressed the type of comfort researchers strive for. Mariela, a twenty-nine-year-old with an intersex trait, summarized that comfort: “Well, I guess I might’ve said the same things to someone else, be it a doctor or a total stranger, and in the back of my mind I would’ve been like, ‘What do they think about that?’ Or ‘What, are they trying to make up their own mind about me?’ Or how I feel about things, I would worry about what they were thinking.” Karen, a fifty-two-year-old with an intersex trait, put it similarly:

Do I feel different talking to you about it? Yeah, of course I do. And in a good way. Because first of all, you are a person with a DSD and so you have a level of sensitivity to this topic that a lot of other people don’t, and I think that that’s a good thing. I don’t translate that as you have a whole

lot of preconceived notions about it. Maybe you do, I don't know. But at a certain level, I don't care whether you do. I know that you're asking questions and you're asking them in a way that hasn't been asked before.

Although I don't necessarily see my personal experience as the sole cause of my ability to ask questions "in a way that hasn't been asked before," I do believe that my initial insider/outsider status uniquely positioned me to ask questions to a diverse group of people that other researchers might not have thought about or have access to, given their outsider status. This enabled the collection of more complete information.

Turning the Methodological Lens

In 1902, sociologist Charles Horton Cooley introduced the concept of the "looking-glass self." In short, this concept suggests that individuals see and consequently construct themselves in relation to how they believe they are perceived. Cooley argues, "Each to each a looking-glass, Reflects the other that doth pass" (152). We can apply the looking-glass self to research methodology, specifically the collection of data. Cooley maintains: "As we see our face, figure, and dress in the glass, and are interested in them because they are ours, and pleased or otherwise with them according as they do or do not answer to what we should like them to be; so in imagination we perceive in another's mind some thought of our appearance, manners, aims, deeds, character, friends, and so on, and are variously affected by it" (152).

Turning the methodological lens on myself, I realized that in all of my field notes, I mentioned what I was wearing and how my hair was styled, despite the fact that, outside of those notes, I never consciously acknowledged that I was altering my presentation for data collection purposes. For example, after one interview I wrote:

Ashley, my hair stylist, straightened my shoulder length dark brown hair late last night. I was worried that my hair would get messed up while sleeping, or if not while sleeping, get messed up on the very early flight out of Chicago this morning, but thankfully it didn't. Note to self: I really can't wait until I can chop off this hair. However, I really am afraid that if I did, parents won't speak to me, especially those who are really

homophobic. While short hair isn't necessarily a sign of being gay, I feel [that] my height (5'10") coupled with the fact that I am very overweight will result in [my] being read as a butch lesbian. Can you imagine that? A parent who wants to express to me their biggest, darkest fear about their intersexual child being gay wouldn't be able to . . . or at least wouldn't feel comfortable because, in essence, they would be directly insulting me. It's a good thing I have Ashley to straighten my hair . . . and it's a good thing my body blocks the hormones that would likely result in [my] having the type of hair that needs daily washing Let's face it, I have hair like my grandmother's that only needs to be washed once a week, if that! I really can't wait to cut my hair . . .

Clearly I was making decisions about my presentation throughout data collection. However, I never really considered this as a theme until I re-read my field notes during data analysis. As I looked back, I realized that I went an entire year without cutting my hair. After having longer hair for more than a year, I simply couldn't continue with it, so I cut it all off during the last summer of data collection. Even after it was short, when I was in the field I regularly found myself styling my hair in a more feminine way than its usual stereotypically butch look.

There is nothing new in the insight that we choose hairstyles based on how we want to be perceived. My point here is not so much about my hair length or style; rather, it is that as a researcher I made decisions about the length and style of my hair given how I believed my participants would perceive me. In this way, I build on sociologist Sara Crawley's point that "gender identity is always dependent on how audiences will allow us to see ourselves. . . . [C]lothing is more than outward performance. It is also inward performance" (2008, 377). When I interviewed people who I knew identified as gay, lesbian, or queer, my self-policing of gender, which I assumed would be a marker of sexuality, was absent. I wore what I wanted to wear, regardless of how I might be perceived, and similarly styled my hair. In this regard, I constructed myself as queer for the queer people I interviewed and as straight/normative for all others. I was, as sociologist Carla Pfeffer (2014) articulates, accomplishing a gender and sexuality; however, later, after considerable reflection, I realized I was subconsciously presenting myself as a straight woman, rather than as a queer person, in certain "field" instances, in an

attempt to minimize any number of limitations I might have encountered throughout data collection, given my queer identity.

The existence of the looking-glass self in the methodological arena is what interests me here. While interview effects have long concerned survey methodologists¹⁹ and qualitative researchers²⁰ alike, their focus seems to overlook how we, as researchers, shift our identities to appease our own assumptions. In some cases, this might mean constructing a visible self that is in direct opposition to the way we believe we will otherwise be perceived. Research shows that by constructing an identity tied to a university, researchers can increase our response rate as a result of the legitimacy implicitly conferred by the academy.²¹ Consequently, researchers usually make their institutional affiliation known during data collection. The new element here is that when studying issues of gender and sexuality, researchers may present themselves in ways related to how they assume they will be perceived, not how they actually are being perceived. The implication of this observation is that researchers may be, consciously or not, self-policing their gender presentation.

Organization of This Book

Although methodology is important in any empirical project, it is at the heart of *Contesting Intersex* given my unique position as a researcher and the nature of my data. Thus it has been the primary focus of this introductory chapter.

In chapter 2, I explore the institutional level of gender structure by focusing on key social movement organizations in the intersex rights movement and the transformation of intersex rights advocacy from “collective confrontation” to “contested collaboration.” Intersex social movement organizations (ISMOS) are especially important because, as I will show, they can serve as vehicles for influencing public ideologies about intersex and ultimately changing medical care. My analysis begins with a discussion of the ISMOs I studied (and from which I recruited research participants): ISNA, Accord Alliance, AISSG-USA, and OII. The early years of intersex activism, I argue, involved individuals with intersex traits coming together in a display of what Nikolas Rose and Carlos Novas (2005) define as a rights biocitizenship: “activism such as campaigning for better treatment, ending stigma, gaining access to ser-

vices, and the like” (442). This particular employment of a rights biocitizenship centered on a collective challenge to the medical profession’s approach to intersexuality; thus I label this period “collective confrontation.” I also make the case that throughout—and beyond—this period of intersex activism, electronic media were critically important in connecting people across the intersex community. This digital link is what Rose and Novas conceptualize as a digital biocitizenship. Digital biocitizenship enabled individuals in the intersex community to learn about intersex from one another in their own space, rather than in a space created and controlled by the medical community, which resulted in what Rose and Novas call informational biocitizenship: highly specialized knowledge about one’s trait. I next describe the emergence of DSD language and the community conflict about terminology that followed; this conflict marks the current period, which I label “contested collaboration.” Today’s intersex advocacy reflects disagreements and disputes exacerbated by DSD language, as some members of the community want to work with medical professionals to change intersex medical care, while others resist such collaboration. Although the intersex community and its social movement organizations were never monolithic,²² I show that the introduction of DSD nomenclature heightened differences across the community and the ISMOs in ways that further divided individuals with intersex traits.

Chapter 3 continues to address the institutional level of gender structure but focuses specifically on the medical management of intersex traits. I argue that insights from the sociology of diagnosis—specifically Annemarie Jutel’s (2011, 2009) theoretical insights about diagnostic naming—can help us understand the contemporary medical management of intersex, specifically why and how medical experts so quickly embraced DSD language. Today, it is rare to find a medical expert who speaks or writes about intersex without using DSD terminology. Chapter 3 tells the story of how this circumstance came to be. It begins with a discussion of John Money’s model for treating intersex, which dominated intersex medical care for much of the second half of the twentieth century. Although Money was once a highly regarded psychologist at The Johns Hopkins Hospital, I revisit the events that led to the discrediting of his research and the collapse of his reputation as the leading expert on intersex. Against the background of this important history, I

show how contemporary U.S. medical experts on intersex, like much of society, tend to hold narrow, essentialist understandings of sex, gender, and sexuality. The danger in medical professionals' holding these views is that they often are used to justify medically unnecessary and irreversible surgical interventions on intersex bodies, which have long-lasting implications for intersex people. Taking into account these two realities alongside 1990s intersex activism (discussed in chapter 2), I argue that medical professionals took so quickly to the new DSD nomenclature because it allowed them to escape their tainted history of intersex medical care. With medical authority and jurisdiction over the intersex body in jeopardy, the new language allowed medical professionals to reassert their power over intersex. Medical professionals no longer treat intersex traits; they treat DSD and in doing so maintain their authority.

In chapter 4, I highlight the individual level of gender structure. Rose and Novas's (2005) discussion of biological citizenship again comes into play, but here I focus on biological citizenship at the level of the self. This shift is possible because Rose and Novas conceptualize biological citizenship as "both individualizing and collectivizing" (2005, 441). Biological citizenship at the individual level is particularly concerned with how individuals use biomedical language to describe aspects of the self. I contend that, for intersex people, biological citizenship at this level is accessible only to those willing to engage with DSD nomenclature (see also Rose 2007, 2001).

My argument about the relationship between DSD terminology and access to biological citizenship begins with a discussion of the emotional and sexual struggles faced by individuals with intersex. While these struggles might seem to be the consequence of medically unnecessary surgical interventions, those who were not surgically modified reported similar difficulties. This leads me to conclude that the struggles associated with intersex do not derive exclusively from the scalpel but rather reside within the broader medicalization²³ process, including the pathologization of the intersex body. For this reason, I fear that DSD terminology, if not approached carefully, is potentially dangerous to the intersex community. *Disorder of sex development* implies that one has an abnormality or, worse, is abnormal.

Because *DSD* was formally introduced by the powerful institution of medicine, the intersex community has no choice but to engage with it.

Those who embrace DSD language tend to hold more essentialist understandings of gender—that is, to see gender as biologically prescribed. Embracing DSD terminology puts an individual in a position to access biological citizenship and, most important, its benefits, including support from medical providers and family members; but this access comes at a cost, notably anxiety about feeling abnormal, that DSD language inherently perpetuates. Those who hold more socially constructed views of gender tend to reject DSD nomenclature on the grounds that its pathologizing terminology conflicts with how they understand their intersex bodies and ability to “do gender.”²⁴ Those who dislike DSD language may still identify as male or female, presenting themselves with masculine or feminine cues such as clothing, hairstyles, and the like, but because they don’t see themselves as having a *disorder*, they seem to have difficulty accessing biological citizenship and the benefits it can afford. Without access to biological citizenship, individuals are left with minimal, if any, support from medical providers and family members. On a positive note, people who reject DSD language tend to describe more positive senses of self. Because they don’t feel that their intersex trait is an abnormality, they do not feel abnormal.

Those who neither embrace nor reject DSD nomenclature give us important insight into the workings of terminological preferences. By being flexible with terminology, people position themselves to have more access to biological citizenship—and its benefits—while also holding a positive intersex identity. In other words, people can selectively employ whichever terminology they believe will be most beneficial at any given time. If they desire support from medical providers and/or family members, they can adopt the medicalized DSD nomenclature. If they begin to feel abnormal, they can embrace intersex language and the notion that intersex is a natural variation of the body. However, I maintain that this flexible access to biological citizenship necessitates an understanding that sex, gender, and sexuality, as well as diagnoses, are socially constructed phenomena.

In chapter 5, I turn to the interactional level of gender structure to investigate how parents of intersex children reach decisions about medical intervention. The chapter begins by looking at how the medical profession presents the intersex trait to parents and how parents respond. I argue that medical professionals construct the intersex trait as a medical

emergency that must be addressed immediately and in a medical setting. This creates what Giorgio Agamben (2005, 2000) describes as a state of exception. Medical professionals who frame intersex as an emergency are creating a state of exception that allows them to abandon medical ethics that warn against performing medically unnecessary surgery on children. Once the intersex trait is presented as an emergency and the state of exception is established, medical providers tend to inundate parents with information about intersex. However, the information they present focuses on the alignment of sex, gender, and sexuality as essentialist characteristics of the body, laying the groundwork for justifying medically unnecessary interventions, notably irreversible surgical procedures that many doctors continue to, even today, recommend without any hesitation to parents of newly diagnosed children.

Relying once again on Rose and Novas (2005; see also Rose 2007, 2001), I show how medical professionals then place the responsibility for medical decisions entirely on parents, thereby avoiding responsibility for questionable interventions. Most important, I argue that when parents are exposed to a different kind of information—that is, information which originates in the intersex community rather than in the medical profession—they are more likely to delay or even refuse medical recommendations. Such questioning of medical recommendations directly challenges medical authority and changes the standard course of intersex medical care. Those who obtain information from the intersex community after consenting to medical procedures tend to report a tremendous amount of guilt, but they too challenge medical authority by advising other parents in the intersex community to question the necessity of medical interventions.

Despite their challenges to medical authority, I find that parents of intersex children are not as divided over DSD terminology as intersex adults. Although not all parents embraced DSD nomenclature, many did. While views on DSD language among adults with intersex traits tended to coincide with conceptualizations of gender as either an essentialist characteristic of the body or a socially constructed phenomenon, this pattern was not observed among parents. Their children's intersex traits challenged many parents to adopt more socially constructed views of gender, making conceptualizations of gender less relevant to their positions on nomenclature. Instead, their terminological preferences

seemed to have more to do with their acceptance of LGBT communities. Parents who embraced DSD language tended to be critical of the move to include an *I* for *intersex* on the LGBT abbreviation, leading me to believe that homophobia fueled at least some of their terminological preference.

Chapter 6 concludes *Contesting Intersex*. It begins with the public attention intersex has recently received. I focus specifically on a groundbreaking 2013 lawsuit filed in both federal and state courts against “South Carolina Department of Social Services (SCDSS), Greenville Hospital System, Medical University of South Carolina and individual employees” by parents who adopted a child with an intersex trait.²⁵ I then turn to the possibility for positive social change in the form of practical actions that intersex activists and allies can take to decrease intersex stigma and the shame and secrecy that surround it. These actions include: (1) continuing to fight for the elimination of medically unnecessary surgeries; (2) collaborating with medical allies; (3) forging connections across groups in the intersex rights movement with a goal of increasing gender, racial, and class diversity across and within intersex organizations; (4) overcoming the fear of public exposure; (5) engaging with formal and informal feminist scholarship; (6) recognizing that social constructions—most notably sex, gender, sexuality, and medical diagnoses—drive inequalities in our community; and, most important, (7) valuing the voices of intersex children in the evaluation of intersex medical care.

An Analysis from Within

My personal experience with intersex has substantially shaped my career in unimaginable ways, of which *Contesting Intersex* is the most significant piece of evidence. There is no question that my lived familiarity with intersex has shaped this project from conceptualization to data collection to data analysis. However, throughout each stage, I have also stayed true to feminist methodologies. I supplemented interviews with ethnographic observations; I recognized patterns; and, most important, I questioned data that seemed to deviate. This process involved returning to the data on numerous occasions to revise my typologies. Many times throughout data collection I thought I had found a pattern only

to have it disrupted by a particularly informative interview. Following sociological tradition, I continued this process until I was confident the patterns I observed were as stable and predictable as possible. I imagine that some will read this analysis with trepidation or skepticism, given my position in the community, and I welcome such readings. However, by the end of my data collection, I was convinced that I had captured an accurate account of the U.S. intersex community at this point in history. This project has been incredibly invigorating for me personally and professionally, and I hope it similarly invigorates others, whatever their connection to the intersex community.